

the Senator from New Mexico and for myself, and the vote to occur after the already scheduled vote. I ask that it be in order to ask for the yeas and nays now.

The PRESIDING OFFICER. It is in order to request the yeas and nays.

Mr. STEVENS. I do request the yeas and nays.

The PRESIDING OFFICER. Is there a sufficient second?

There appears to be a sufficient second.

The yeas and nays were ordered.

The PRESIDING OFFICER. Without objection, it is so ordered. The request is agreed to.

Mr. STEVENS. Mr. President, parliamentary inquiry. I understand the Senate will stand in recess at 12:30.

The PRESIDING OFFICER. Under the previous order, that is correct.

Mr. STEVENS. I yield the floor.

The PRESIDING OFFICER. The Senator from North Dakota.

Mr. DORGAN. Mr. President, the legislation pending before the Senate is the emergency supplemental bill dealing with Iraq; and that has to do with security: security for our troops, security in Iraq. But there are other issues of security that affect us in our country: issues of security that deal with protecting our homeland. We provide critically needed funds to try to prevent another terrorist attack on our soil.

So I was surprised, as I was traveling the other day, to hear the President talk about using Homeland Security assets to track down Americans who are traveling in Cuba illegally and punishing those Americans.

As you know, it is currently illegal for Americans to travel in Cuba, except by a license given by the U.S. Treasury Department. The fact is, though, that there are many Americans who do go to Cuba. Many go because they think it is their right as Americans to travel freely, and in many cases, they go because they are not aware that they are breaking any rules.

I believe the travel ban unfairly punishes American citizens. In an attempt to take a slap at Fidel Castro, it ends up restricting the right of American people to travel. Many of us here think that makes no sense at all.

When I heard the President describe his interest in having Homeland Security people track down American tourists traveling in Cuba, I thought I would come to the floor of the Senate, and talk about a grandmother named Joan Slote. As you can see from this picture, Joan is in her mid 70s. She is a Senior Olympian. She is a bicyclist. She bicycles all over the world. She is in her mid 70s. And she joined a bicycle tour of Cuba, with a cycling club from Canada. They bicycled in the country of Cuba for, I believe, 8 or 9 days.

Joan Slote came back to this country from Cuba, and later on she was off to Europe where she was on a bicycle tour. While she was in Europe, she learned her son had brain cancer, and

she rushed back to the United States, and just stopped at her home for a minute, and then rushed down to be with her son and attended to her son, who later died of brain cancer.

When she finally came back to her home, apparently there was a letter waiting for some long while from the U.S. Treasury Department that said: Oh, by the way, you traveled to Cuba with a bicycle club from Canada, and that was illegal, and so we are administering a \$7,630 fine.

So Joan Slote, this mid 70s grandmother—no threat to this country for sure—is one of those Americans who is now being punished by the U.S. Government for travel in Cuba.

Now, we have folks down at the Department of the Treasury in an organization called the Office of Foreign Assets Control, or OFAC for short—and that is the organization that is charged with tracking money to terrorist groups to protect our country. But instead of focusing on that critically important mission, OFAC officials are tracking retired grandmothers who are riding a bicycle in Cuba and try to slap them with a big fine.

And now the President says: Oh, by the way, I would like to get more involved here. I want the Homeland Security Department tracking these people who are traveling to Cuba.

I thought our interest here in the Senate was to fund a Homeland Security agency to protect our country against the threats of terrorists, not to chase little old grandmothers who take a bicycle trip to Cuba.

Incidentally, OFAC finally negotiated with a \$2,000 fine for Joan Slote. After I intervened, they said: All right, the \$7,600 fine we will reduce to \$2,000. So she sent them the money. But do you know what they did then? They sent a collection agency after her and told her they were going to begin to garnish her Social Security payments. Why? I do not have the foggiest idea. I guess it is just a bureaucratic mess.

But I was just thinking as I was driving down the road the other day, hearing President Bush say we have to get tough on Cuba, we are going to take Homeland Security people to go chase American tourists in Cuba.

The interesting thing is, Americans can travel virtually everywhere. You can travel to Communist China. Yes, that is a communist country. You can travel to Vietnam. Yes, that is a communist country. But you cannot travel to Cuba. And we are going to use Homeland Security assets—people, time, money—to go track down little old ladies who are bicycling in Cuba?

Are we really threatened by the poor guy who took the ashes of his dead father to Cuba, which was his father's last wish, to be sprinkled on the lawn by the church where he ministered in Cuba many years before?

Yes, they tracked that fellow down for taking his dad's ashes to Cuba. They fined him \$7500.

It is story after story after story like this.

And now the President wants people in Homeland Security tracking Americans to punish Americans for traveling in Cuba.

What about homeland security? How about tracking terrorists? Let's track terrorists, not retired grandmothers who are riding bicycles.

Marshall McLuhan once said: I don't always believe everything I say. I thought to myself, that must surely have been the case in the White House when the President announced we are going to take Homeland Security Agency resources and start tracking American citizens so we can slap big fines on them for traveling into Cuba. This is preposterous. What on Earth can the President be thinking?

I have talked to Joan Slote. She is just one of many examples of ordinary U.S. citizens who meant absolutely no harm. I have talked to another retired grandmother from Wisconsin. She traveled to Cuba innocently and rode a bicycle as well. I have talked to many such folks. I held a hearing on this. I had people show up who described their travel to Cuba. They did not know it was illegal but—guess what—they have the Federal Government after them.

In an attempt to slap Fidel Castro, we are punishing American people. We are restricting the right of the American people to travel. And now the President gets into the act, which, I assume is about Florida politics, and says, oh, by the way, I want to divert Homeland Security assets to see if we can't get tougher on people like Joan Slote.

This issue involves wasted resources, that could and should be spent on real threats to our homeland security. Homeland security is about protecting this country from the threat of terrorists, not chasing senior citizens riding around on bicycles.

That is where the homeland security assets ought to be employed. That is where the Department of the Treasury assets ought to be employed, protecting our country from the threat of terrorist attacks, not chasing Joan Slote. My hope is that perhaps they will have another meeting at the White House and rethink this and finally do the right thing, at least meet some basic test of common sense.

I yield the floor.

RECESS

The PRESIDING OFFICER. Under the previous order, the hour of 12:30 having arrived, the Senate will stand in recess until the hour of 2:15 p.m.

Thereupon, at 12:30 p.m., the Senate recessed until 2:15 p.m. and reassembled when called to order by the Presiding Officer (Mr. VOINOVICH.)

GENETIC INFORMATION NONDISCRIMINATION ACT OF 2003

The PRESIDING OFFICER. Under the previous order, the hour of 2:15 p.m. having arrived, the Senate will resume

consideration of S. 1053, which the clerk will report.

The assistant legislative clerk read as follows:

A bill (S. 1053) to prevent discrimination on the basis of genetic information with respect to health insurance and employment.

The PRESIDING OFFICER. Under the previous order, there will be 15 minutes of debate equally divided, followed by a vote on passage of the bill. Who yields time?

The Senator from New Hampshire.

Mr. GREGG. Mr. President, I yield myself such time as I may consume.

This is important legislation. It has been 6 years in gestation. It is legislation which is not only important to our research community but, more importantly, it is a major piece of civil rights legislation in that it protects people in their employment and in getting health care.

Essentially, we are in a new world in the community of health care where you will actually be able to go to your doctor someday not too long from now, and probably in some instances even today, and he will be able to tell you some of the most severe illnesses projected for your lifetime. That is called genetic information. It is great medical news that we have moved this far, and there is a lot that will occur that is positive as a result.

The other side of the coin is this information could be used arbitrarily, unsuspectingly, or even intentionally to harm your employment or your capacity to get health insurance. This legislation corrects that concern. It makes it possible to continue genetics research without people having to be concerned about the way their personal genetics information may be used. That is why it is important.

A lot of folks have worked very hard on this bill. Senator KENNEDY has worked tirelessly to pass it. Senator DASCHLE has worked aggressively to pass it. Senator JEFFORDS, when he was chairman of the committee, worked very hard.

On our side of the aisle, Senator ENZI has made a major contribution in the area of employment, and Senator SNOWE was one of the originators of the initiative.

At this point, I reserve the remainder of my time and yield the floor.

The PRESIDING OFFICER. The Senator from Massachusetts.

Mr. KENNEDY. Mr. President, I see one of the primary sponsors, the Senator from Maine. I will withhold and make comments when she finishes.

Mr. GREGG. I yield 3 minutes to the Senator from Maine.

Ms. SNOWE. I thank the Senator from New Hampshire, chairman of the committee, whose guidance throughout this process ultimately culminated in this most significant piece of legislation. I express my appreciation to him and to the Senate majority leader, without whose leadership this legislation would not be possible, and to the Democratic leader as well, and to Sen-

ator KENNEDY, Senator ENZI, and, of course, Senator JEFFORDS, who sponsored this effort with me some 7 to 8 years ago. I also acknowledge the presence of Representative SLAUGHTER from New York who has led the effort in the House for approximately 8 years at this point.

This is the culmination of bipartisan efforts over the last 8 years and over the last 2 years of bipartisan negotiations where we were able to merge the differences between the legislation that I introduced and that was introduced by Senators DASCHLE and KENNEDY.

The fact is, since April of 1996, when I first introduced the Genetic Non-discrimination Health Insurance Act, science has continued to hurdle forward, further opening the door to early detection and medical intervention through the discovery and identification of specific genes linked to diseases such as breast cancer, colon cancer, cystic fibrosis, and Huntington's disease. That 1996 legislation recognized that with the progress in the field of genetics accelerating at a breathtaking pace, we needed to ensure that with the scientific advances to come, we would advance the treatment and prevention of disease without advancing a new basis for discrimination.

Certainly everything changed with the unveiling of the first working draft of our entire genetic code. It became all the more imperative that we respond with legislation that would at once allow the tremendous promise of this breakthrough while at the same time protect the American people from the dark side of discrimination.

Because there has been so many other scientific advancements this carried with it, not only the prospect of scientific and medical discoveries, such as improved detection and earlier intervention, but also the potential for harm and abuse, every day since—absent enactment of this type of legislation—has been a day we have left the full potential of the human genome untapped.

This is no solution in search of a problem. To the contrary, the very real fear of repercussions from one's genetic makeup was specifically brought home to me through the real-life experience of one of my constituents, Bonnie Lee Tucker. Bonnie wrote to me about the fear of having the BRCA test for breast cancer. She was in a family who had nine members with breast cancer. She herself is a survivor. She feared having the BRCA test because she worried it would ruin her daughter's ability to obtain health insurance in the future.

I ask that everybody support this legislation because, clearly, this is one of the most significant groundbreaking pieces of legislation we could have in the area of medical health care.

The PRESIDING OFFICER. The Senator from Massachusetts is recognized.

Mr. KENNEDY. I yield myself 2½ minutes.

First, I thank my colleague and friend, the chairman of the committee,

Senator GREGG, for prioritizing this issue. It is a matter of enormous importance. I thank him and I thank Senator SNOWE, who has been a leader on this issue for a number of years. This has truly been a bipartisan effort. I also thank our majority leader, Senator FRIST, also a doctor, who understands this issue and has been very cooperative; Senator ENZI, who chairs a subcommittee in this area of policy, has helped to advance this program. We are grateful for the strong bipartisan ship. I wish to recognize Congresswoman SLAUGHTER, who initiated the original legislation, and today we pay tribute to her.

Also, I thank our Democratic leader, TOM DASCHLE, who, in 1997, was the first person to introduce the comprehensive genetic discrimination program. Our friend, Senator JEFFORDS, has been an advocate for the elimination of genetic discrimination; TOM HARKIN and CHRIS DODD have been tireless advocates to make sure we got to this particular day.

I am going to yield time to Senator HARKIN in a minute.

In 1964, this Nation passed the important civil rights legislation to ban discrimination in our society in employment and public accommodations, among other things. Then in 1965 we banned discrimination in voting. Then, in 1968, we passed legislation to ban discrimination in housing. Then, under the leadership of my friend from Iowa, in 1990, the Americans with Disabilities Act passed to ban discrimination on the basis of disability. We have also done much to eliminate discrimination on ethnicity, on national origin, and we have made enormous progress in discrimination on gender. We still have not made enough progress on discrimination regarding gay and lesbian issues. Today, we are continuing the march toward equality in the United States, understanding the importance of eliminating discrimination based upon an individual's genetic makeup, in terms of insurance and in terms of employment. We are doing it in a way that is going to guarantee real remedies. This is not just legislation that will be out there and say we are against this form of discrimination; we are providing real remedies. From now on, individuals will know that no matter what their genetic makeup or susceptibility to genetic disease, they may not be discriminated against in the job place or in the provision of health insurance.

This is a major continuing step toward greater equality and the elimination of bigotry and discrimination in our society. It is an important day in the Senate. I commend all of those and the staff for all they have done so well to make it possible.

I yield 3½ minutes to the Senator from Iowa.

Mr. HARKIN. Mr. President, I thank the Senator from Massachusetts for the time. I join with him and others in thanking our leaders for bringing this

bill forward. I congratulate Senator GREGG, chairman of our committee, Senator KENNEDY, ranking member on our side, Senator SNOWE, and all the other Senators they have mentioned, who have worked so hard to get us to this point. Again, I thank the leadership for the vote today.

I was present sort of at the gestation period and finally the birth of the mapping and sequencing of the human genome. What a magnificent step forward this was in terms of our understanding of the underlying basis for many of our diseases and illnesses. This feat of sequencing and mapping of the 3.1 billion base pairs of the human genome, sometimes called "the book of life," opens up a world of possibilities for preventing and curing disease. New genetic tests take the concept of early detection and treatment of disease to levels that were previously only imagined but are now scientifically possible. Discoveries have been made about the genetic basis of many diseases, such as heart disease, diabetes, Parkinson's disease, and asthma. Tests are already available for breast cancer, ovarian cancer, colon cancer, and several other diseases.

But while the potential medical and health benefits of this new technology seem limitless, they cannot be pursued without caution and safeguards against abuse, such as discrimination by health insurers or employers. The Genetic Information Nondiscrimination Act, before us now, addresses these possible abuses. It establishes protections against discrimination based upon genetic information both in health insurance and employment. It is a gigantic step forward, as Senator KENNEDY said, in making sure people are not discriminated against simply because of what their genes are.

While this bill doesn't include everything I believe it should have included, it is a significant step forward for the American people and for our health care system. Under this bill, individuals will finally be protected from discrimination by health insurers or employers based on genetic makeup. Everybody will have the peace of mind to seek answers to questions about themselves without fear of losing their health insurance or their job.

I commend those leaders who have brought this forward and yield back whatever time I may have remaining.

Mr. ENZI. Mr. President, 50 years ago James Watson and Francis Crick discovered the structure of the DNA molecule—the blueprint of life. Their discovery laid the foundation for predicting and treating the hereditary diseases that threaten us.

The completion of the Human Genome Project in April 2003 was a significant step towards this goal. Because of the work of these scientists, we now are able to decipher the exact sequence of the genetic code. This knowledge will allow earlier detection and more effective treatment of genetic illnesses.

However, genetic information brings challenges along with promise. The Genetic Information Nondiscrimination Act will ensure that the promise of genetic information is not hindered by fears about its misuse. This legislation will protect individuals from discrimination in health insurance and employment on the basis of genetic information.

I thank my colleagues on both sides of the aisle for crafting a bill that fairly and effectively protects people against genetic discrimination. In doing so, we have been mindful of existing discrimination and privacy laws and regulations. While the issue is complex, our objective is clear: to encourage people to seek genetic services by reducing fears about the misuse or unwarranted disclosure of genetic information.

Today, we mark the 50th anniversary of Watson and Crick's historic discovery with the passage of the Genetic Information Nondiscrimination Act. With each new advance in genetic science, the significance of this legislation grows. By allaying fears about genetic discrimination in health insurance and in the workplace, this legislation will save lives now and in generations yet to come.

(At the request of Mr. DASCHLE, the following statement was ordered to be printed in the RECORD.)

• Mr. KERRY. Mr. President, it is high time we have a strong genetic information protection law on the books. The Senate bill I am voicing support for today is a step in the right direction. However, while I am pleased to join a bipartisan effort to pass S. 1053, the Genetics Information Nondiscrimination Act, I hold out hope that the enforcement provisions in the bill can be strengthened prior to final passage. The House of Representatives will soon be conducting hearings on the unanimously-passed Senate legislation and will be working to craft their own version of the law. I sincerely hope that the House works to strengthen—not weaken the bill. One area where the bill can be strengthened is to give some real teeth to the enforcement protections. If our goal of limiting discrimination based on genetic information is to be realized, we must work to ensure that those whom we seek to protect can truly use this law to guard against discriminatory actions. •

Mr. DODD. Mr. President, over the past decade, the science of genetics has developed at an astonishing pace. The mapping of the human genome is undoubtedly one of the greatest scientific achievements of my lifetime. We have not even completely grasped the wide array of potential benefits that may come from our newfound genetic knowledge. Certainly, the impact on our health will be profound. Doctors will be able to read our unique genetic blueprints and predict the likelihood of developing diseases such as cancer, Alzheimer's, or Parkinson's. They will also be able to use an individual's ge-

netic information to develop treatments for these same diseases and target individuals with the treatment that will work best for them. This is not science fiction—it is already beginning to happen.

For all the promise of the genetic age, there is also an inherent threat. Science has outpaced the law and Americans are worried, and rightly so, that their genetic information will be used, not to improve their health, but to deny them health insurance or employment. There is no information more personal and private than genetic information and no information more worthy of special protection. Our genetic code is the very blueprint of ourselves. It is with us from birth, and to some extent it determines who we will become. What an incredibly powerful tool, with its vast potential to help us live healthier lives. But the nature of genetic information also makes it dangerous to the individual if used incorrectly.

This is why so many of us, on both sides of the aisle, saw the need several years ago for legally enforceable rules to maximize the potential benefits of genetic information and minimize its potential dangers. The legislation before use represents a culmination of the efforts of many of us to establish such rules. It represents an enormous step forward, and I wish to acknowledge the hard work of everyone who was involved in crafting this legislation.

This bill provides significant new protections against the misuse of genetic information. It ensures that Americans who are genetically predisposed to health conditions will not lose or be denied health insurance, jobs, or promotions based on their genetic makeup. Reaching an agreement on this legislation means that our laws dealing with genetic information can begin to catch up to the reality of our technological capability in the field.

With these protections in place, individuals need not feel reluctant to get the tests that may save or improve their lives. Although the Americans with Disabilities Act, ADA, and the Health Insurance Portability and Accountability Act, HIPAA, took important steps towards preventing genetic discrimination, this legislation is more specifically tailored to prohibiting its misuse. Health plans and health insurance issuers will not be allowed to underwrite, determine premiums, or decide on eligibility for enrollment based on genetic information. Employers will not be allowed to alter hiring practices based on genetic information. The American public can feel secure in the knowledge that their genetic blueprint will not be used to harm them, that a genetic marker indicating a possible illness later in life will not cause them to lose a job or health insurance.

This is by no means a perfect or complete bill. In particular, while it poses some important limitations on the collection of personal genetic information

by insurance companies, it would allow them to collect this information, without consent, once an individual is enrolled in a health plan. While insurers are expressly prohibited from using this information for the purposes of underwriting, I am concerned that once they have this information, it may be difficult to control how it is used and who has access to it. We all know from experience that the difficulty of protecting information increases exponentially with each additional person who has access to that information.

Let me add that, during negotiations, good faith attempts were made on both sides to address these concerns. Unfortunately, we could not reach an agreement on this issue that made all parties comfortable. As a result, the bill falls short of offering comprehensive privacy protection. Personal genetic information is already widely available, and the risk of abuse is high. Health plans and employers will have legitimate reasons for collecting genetic information. But individuals should be given the power to regulate how such information is distributed, and with whom it is shared. As this bill becomes law, and I sincerely hope it will, I will monitor closely how it is implemented, and the extent to which privacy is protected. We may need to revisit this issue in the future.

Despite this shortcoming, I support this bill, as it represents a vast improvement over current law in many ways. I hope that it will become law in the very near future. We all should feel free to make our health care decisions based on our health care needs, not based on fear. Today, we are close to making that goal a reality.

Mrs. CLINTON. Mr. President, S. 1053 has the laudatory goal of prohibiting genetic discrimination. Genetic discrimination has many victims, and their stories are wrenching. There are those who cannot get coverage, as well as those who lost job opportunities. But I want to make sure we don't forget another category of victims—those who forego important tests out of fear that they will be victimized. According to a recent JAMA article, 57 percent of patients at risk for breast and ovarian cancer declined a needed genetic test that could have guided prevention and treatment interventions. That is why our goal should have been not just to pass a bill, but to pass a credible bill so that people have enough confidence in our work to go out and get the health services they need.

Unfortunately, I am concerned that the enforcement provisions of S. 1053, particularly in health insurance, are not strong enough to accomplish the legislation's goal.

Our Nation has made significant investments in genetic research. This research could one day lead to cures or preventions for diseases such as cancer. This investment in genetic research will prove futile if the result is not better health care. Individuals must participate in genetic research if this Na-

tion is to reap the rewards of our investment and individuals must have confidence in the results of genetic research in order to address their personal health issues. However, as genetic information is increasingly revealed, great harm can occur. As President Bush acknowledged in his June 23, 2001 radio address:

This knowledge of the code of life has the potential to be abused. Employers could be tempted to deny a job based on a person's genetic profile. Insurance companies might use that information to deny an application for coverage, or charge excessive premiums.

Americans have already shown that they will not fully participate in genetic research or take advantage of genetic technologies until they believe that they are protected against genetic discrimination in health insurance and employment. Without protection, patients fear disclosing their family history, yet this hesitancy may impact the care that they and their families receive.

As you recognize, genetic information is uniquely personal information. It is fundamentally different from other medical information. Because genetic information can be used against an individual and an entire family, it enables a new form of discrimination. It deserves strong enforcement and should not be treated the same as other information in a medical record.

In order for S. 1053 to achieve its purpose, individuals must have confidence in its enforceability. That confidence will be difficult to instill without mechanisms such as access to a court or comparable forum to seek redress for violations of the statute. In addition, it is important that the public feel confident that violations are unlikely. This reassurance can only come from legislating strong enforcement and deterrence mechanisms. I would have liked to see the enforcement mechanisms and remedies in S. 1053 strengthened to provide for compensation for economic and non-economic damages and strong punitive provisions. If there is no redress for individual harm and if nominal fees are the only accountability mechanism in place, there is little to deter health insurers and employers from using genetic information in violation of the law.

However, I believe that this bill does make a start in the direction of supporting the principle that advances in science should help move civilization forward, not to reverse our progress. Discrimination based on genetic information would be a step backward for civil rights and human dignity. That is why I support action today to begin addressing this issue, and hope that in the future we will reinforce today's action with improvements to secure justice and civil rights for all Americans.

Mr. JEFFORDS. Mr. President, today's consideration of S. 1053, the Genetic Information Nondiscrimination Act, is the result of almost 6 years of effort, so I am especially pleased that

we are here today to consider and pass this bipartisan legislation. For the first time, S. 1053 will prohibit discrimination against individuals based on their genetic make-up in both health insurance and employment. This legislation represents a major contribution to civil rights law. It is a victory for consumers, health insurers and health care providers; and it is a victory for employees and employers.

The issue of genetic nondiscrimination has concerned me for many years, and I have been pleased to work with many members of the Senate to craft this legislation. The measure we are considering today is the result of many years of effort and the contributions of many individuals. It is an example of the progress that can be made when the Senate seeks to negotiate and compromise on a bipartisan basis.

Together with the much deserved excitement over the potential of genetic research there have also been long standing concerns that genetic information, in the wrong hands, could be misused. Many people have argued that an individual's genetic information—that might indicate a predisposition to a particular disease—could be used to deny that individual health insurance or employment opportunities. The promise of better health would instead become a potential for greater discrimination and disadvantage. The Genetic Information Nondiscrimination Act of 2003 is designed to address those concerns.

Existing antidiscrimination law has been enacted over the years as a means of correcting long-standing abuses in voter rights, employment, housing and education. But under current law a person who has suffered employment or health insurance discrimination because of their genetic makeup has very little, if any, recourse to legal remedies. This legislation addresses this problem by creating new enforceable rights for individuals similar to those available under existing civil rights, education and fair employment law.

It is important to note that to date, there has not been a pattern or clear prevalence of genetic discrimination. But there is anecdotal evidence that people have refused to take genetic tests because of their fear that the predictive information would lead to discrimination. We know the science is rapidly moving forward and we are learning more every day about the "predictive" correlation between genetic markers and certain diseases. It is not difficult to imagine such discrimination occurring in the near future. So in a sense, we can take that rare opportunity to be ahead of the curve and enact legislation to preempt discriminatory practices and prevent them from ever happening.

I believe the compromise legislation we consider today will be successful in preventing abuses in the insuring of health services and employment. However, we must remain vigilant against this type of discrimination from ever

getting a foothold in our society and if this measure proves insufficient and needs to be strengthened then we will be back and that effort will have my support.

There are many Members who have played a significant role in bringing together two different, though similar bills. My friend, Senator SNOWE, led one effort in which I was proud to join together with Senators FRIST, ENZI, COLLINS, and HAGEL. In another effort, Senator DASCHLE was joined by Senators KENNEDY, DODD, and HARKIN. That measure focused attention on the need for employment provisions and contributed to a better understanding of the many critical and complex definitions. Finally, I want to salute Senator GREGG, who as chairman of the HELP Committee devoted his energies to finding a middle ground that has made this legislation possible.

I am pleased at the willingness both sides have shown to work through the many difficult aspects of this key issue. Through many meetings and discussions we have been able to reach agreements on many important issues, and improve the legislation. I look forward to continuing this cooperative approach as we move to enact this important and landmark initiative and I urge our colleagues in the House to pass it as well. This legislation is supported by the President and it is my hope that we can enact it into law before the end of this Congress. I urge all of our colleagues to vote in its favor.

Mr. CORZINE. Mr. President, I am pleased that today the Senate is considering legislation designed to prohibit discrimination in health insurance and employment based on genetic information.

In the last decade, biomedical researchers have made great strides in genetic research. While these discoveries are critical to researching treatments and, ultimately, discovering cures for many diseases, this information also has the potential to be used to deny health care insurance or employment to an individual who has a genetic predisposition to an illness. That is why we must make it illegal for employers and health insurers to discriminate against individuals on the basis of their genetic information.

S. 1053 is an important step, but it is only a first step. Any legislation addressing this issue must include strong enforcement and deterrence mechanisms. As this legislation moves forward, I hope its enforcement provisions will be strengthened. Without strong accountability provisions, there is little to deter employers and health insurers from using genetic information inappropriately.

In addition, I hope that when this legislation is conferred, the conferees will find ways to strengthen the privacy provisions. It is essential that our laws keep pace with technological advances and that we continue to protect the privacy of our citizens. Advances in technology cannot place fundamental American rights at risk.

Despite my concerns about the enforcement and privacy provisions, I believe this legislation is a critical first step and look forward to working with my colleagues to continue addressing the important issue of genetic discrimination.

Mr. SCHUMER. Mr. President, today, the Senate came together to pass S. 1053, the Genetic Information Nondiscrimination Act. I cast my vote in favor of this bill because I think it takes an important first step in the right direction. It is my view, however, that the bill does not go far enough. I commend my colleagues for their efforts to craft a bipartisan compromise, but I have serious concerns that the final bill does not include adequate enforcement provisions.

The Genetic Information Nondiscrimination Act prevents employers and insurance companies from treating individuals differently because of their genetic predispositions. It stops a health insurance company, for example, from charging an individual a higher premium because her mother had breast cancer.

S. 1053 does not, however, have adequate enforcement provisions. There is no recourse for individuals who feel that their rights under the law have been violated. There is no opportunity for a person to hold his employer accountable for genetic discrimination in a court of law. The current accountability provisions, which consist of nominal fees, are not sufficient in order to protect individuals who have been treated unfairly because of a genetic predisposition.

Therefore, I voted for this bill with some reluctance. I was very pleased to see this issue addressed in the Senate, but concerned that the language of the bill does not adequately protect the people for whom it was written. I hope that there will be opportunities in the future to strengthen this bill and ensure the rights of victims of genetic discrimination.

Mr. DOMENICI. Mr. President, I rise today in support of the Genetic Information Nondiscrimination Act of 2003, a bill that will prohibit discrimination based on genetic information with respect to employment and health insurance. This bill represents much cooperation on the part of my colleagues, and I want to recognize Senators SNOWE, FRIST, JEFFORDS, DASCHLE, KENNEDY, and also HELP Committee Chairman GREGG, for all the hard work done on this important issue.

I am extremely pleased with today's passage of the Genetic Information Nondiscrimination Act, as it marks a great milestone for those of us involved in the Human Genome Project. It seems only a short time ago that the Human Genome Project was created as a joint effort between the Department of Energy and the National Institutes of Health. What progress we have made.

In the last two years, there have been many events celebrating the comple-

tion of maps of the human genome. The genome map has brought a promise of improved health through revolutionary new treatments for illness and disease. The ultimate result of mapping the human genome is a complete genetic blueprint, a blueprint containing the most personal and most private information that any human being can have. We will now have a wealth of knowledge of how our countless individual traits are determined. And perhaps more important, we will have fundamental knowledge about the genes that can cause sickness and sometimes even death.

Our personal and unique genetic information is the essence of our individuality. Our genetic blueprint is unique in each of us. However, as genetic testing becomes a more frequently used tool, we now must begin to address the ethical and legal issues regarding discrimination on the basis of genetic information. Questions regarding privacy and confidentiality, ownership and control, and consent for disclosure and use of genetic information need to be carefully considered.

An unintended consequence of this new scientific revolution is the abuses that have arisen as a result of our gathering genetic information. Healthy people are being denied employment or health insurance because of their genetic information. By addressing the issue of nondiscrimination, we are affirming the right of an individual to have a measure of control over his or her personal genetic information.

Genetic information only indicates a potential susceptibility to future illness. In fact, many individuals identified as having a hereditary condition are, indeed, healthy. Some people who test positive for genetic mutations associated with certain conditions may never develop those conditions at all. Genetic information does not necessarily diagnose disease; yet, many people in our society have been discriminated against because other people had access to information about their genes, and made determinations based on this information that the individual was too risky to insure or unsafe to employ.

While the issue is complex, our objective is clear; people should be encouraged to seek genetic services and they should not fear its discriminatory use or disclosure. The Genetic Information Nondiscrimination Act is an important first step towards protecting access for all Americans to employment and health services regardless of their genetic inheritance. There is simply no place in the health insurance or employment sector for discrimination based solely upon genetic information.

Mr. KENNEDY. How much time do I have?

The PRESIDING OFFICER. The Senator has a minute and a half.

Mr. KENNEDY. I yield myself the remaining time.

I ask unanimous consent that a statement of the administration's policy be printed in the RECORD.

There being no objection, the material was ordered to be printed in the RECORD, as follows:

STATEMENT OF ADMINISTRATION POLICY

The Administration is committed to enactment of legislation to prohibit genetic discrimination in health insurance and employment. The Administration supports S. 1053, which would bar health insurers from denying coverage to a healthy individual or charging the person higher premiums based solely on a genetic predisposition to developing a disease in the future. The bill also would prohibit employers from using individuals' genetic information when making hiring, firing, job placement, or promotion decisions.

The Administration wants to work with the Congress to ensure that individuals can be certain that they are protected against the improper use of genetic information. Unwarranted use of genetic information, and the fear of potential discrimination, threatens both society's ability to use new genetic technologies to improve human health and the ability to conduct the very research needed to understand, treat, and prevent diseases. Enactment of Federal legislation will help guarantee that the Nation fully realizes the potential of ongoing advances in genetic sciences.

Mr. KENNEDY. Mr. President, it is important to know that President Bush, in 1997, while the governor of Texas, signed a law prohibiting genetic discrimination. He also went to the Nation in a radio address on June 23, 2001 and supported the elements included in this law. We have a very strong Statement of Administration Policy in support of this program.

We thank the President for his strong support and we will work with our Republican friends to try to make sure this message goes to the House of Representatives and that they respond in a similar way.

I hope we will have an overwhelming vote in the Senate today. It is one of the most important bills we will consider this Congress.

I yield back my time.

The PRESIDING OFFICER. The Senator from New Hampshire is recognized.

Mr. GREGG. Mr. President, I thank the Senator from Massachusetts for his aggressive and effective leadership on this issue. I also thank the Democratic leader, who played a major role in this, Senator HARKIN, who has been working on this issue for many years, and, of course, Senator FRIST, also, because he has made this a priority and that is why we are on the floor. This is an issue in which he obviously has a personal interest, with his medical background.

We should also thank one of the groups that really energized this initiative of making lives better through developing the human genome and that is the folks at NIH, led by Dr. Francis Collins. They are the ones who are going to take this knowledge and disseminate it in a way that makes it available to the health community generally and, as a result, improve the lives of literally millions of Americans and potentially tens of millions of people around the world.

This is truly an extraordinary breakthrough in science, but it is important that it be used right and it is important that it not be used in a way that may harm individuals' economic well-being or their capacity to get health insurance. That is why this legislation, at the beginning, is so important. By having it in place, we will be able to energize even more research and more use of the genetic information that is available through science today.

Mr. President, I believe we are ready to vote. I yield back the remainder of my time.

Mr. KENNEDY. Mr. President, I ask unanimous consent to proceed for 10 seconds.

The PRESIDING OFFICER. The Senator has time remaining.

Mr. KENNEDY. I also thank Judy Lichtman, who is president of the Coalition for Genetic Fairness. I wanted to mention her name on the floor. She did a great deal of work, as well as the coalition. We are prepared to vote.

Mr. DASCHLE. Mr. President, a half-century ago, Drs. Francis Crick and James Watson discovered the structure of DNA—a revolutionary breakthrough that enabled scientists to begin unraveling the mysteries of human life and diseases.

Earlier this year, scientists at the National Human Genome Research Institute celebrated the completion of a massive undertaking begun 10 years earlier to map the entire human genetic code.

Our new knowledge about our genetic blueprint has the potential to dramatically improve our health and the quality of our lives. It also has the potential to destroy lives. Which of those two potentials becomes reality depends on whether and how well our laws keep pace with changes in technology.

We know from hearings we held in the Senate that current laws are inadequate to protect Americans from genetic discrimination. We also know that today Americans are not being tested, not taking advantage of medical advances, and not participating in genetic research because of their fear of discrimination. Their fears, unfortunately, are not unfounded.

Almost 2 years ago, I met a man named Dave Escher. Mr. Escher had worked for the same company for more than 25 years and was a good employee. One day, Mr. Escher was told by his employer that he needed to see a company doctor; if he refused, he was told he could lose his job. So Dave Escher saw the doctor.

However, it wasn't until after the doctor's appointment—and only by accident—that Mr. Escher learned that the company's doctors had used his blood to conduct genetic tests for more than 20 medical conditions.

Stories like Mr. Escher's may be relatively rare today, but experts tell us that is largely because genetic testing itself is still relatively rare, and because many people are choosing not to take genetic tests. As testing becomes

more affordable and more common, experts say, the incidence of discrimination is likely to increase dramatically unless we act to prevent such discrimination.

Almost two centuries ago, Thomas Jefferson, one of this country's foremost scientists and original thinkers, wrote that "laws and institutions must go hand in hand with the progress of the human mind. As . . . new discoveries are made [and] new truths disclosed . . . institutions must advance also, and keep pace with the times."

In this age of genetic breakthroughs, it is essential that our laws catch up with the science. We can't afford to take one step forward in science but two steps backward in civil rights. Our laws must specify, clearly and unambiguously, how genetic information may be used and how it may not be used.

Today, after years of discussion and negotiation, the Senate is finally poised to pass bipartisan legislation to protect all Americans against the misuse and abuse of genetic information.

Our bill does three things:

No. 1, it forbids health insurers from discriminating against individuals—denying them coverage, for instance, based on genetic test results.

No. 2, it forbids employers from using genetic information to discriminate in hiring, or in the terms and conditions of employment.

No. 3, it sets privacy standards for access and disclosure of genetic information.

Genetic information should be a private matter—period. It should not be shared with employers or insurance companies without an individual's consent.

For years, experts have urged Congress to pass comprehensive national standards to protect all Americans from genetic discrimination. If we fail to do so, the experts warn, we will almost certainly squander many of the enormous potential benefits of the genetic revolution.

We have been trying to heed that warning for years. I first introduced legislation prohibiting genetic discrimination 6 years ago. Senator SNOWE and many other Senators on both sides of the aisle have been working on this important issue for just as long. After countless hours of tough negotiations, we have finally arrived at a fair resolution that provides important protections for individuals in both employment and health insurance.

Passage of this bill represents a victory for bipartisanship. But more importantly, it is a victory for the American people. Discrimination based on genetic information is just as arbitrary, just as unacceptable, and just as un-American as discrimination based on gender, race, religion, or disability. Like those other forms of discrimination, it should not be allowed in this country.

Again, I thank our colleagues who have enabled us to reach this compromise and I urge all of our colleagues to support it.

There are a few people who deserve special recognition. I particularly want to thank those Senators who have been working on this issue from the beginning and whose contributions were invaluable in reaching this compromise, especially Senators SNOWE, KENNEDY, HARKIN, DODD, JEFFORDS, FRIST, GREGG, and ENZI.

I also want to thank Dr. Francis Collins and the staff at NIH, as well as Kathy Hudson, who heads up the Genetics and Public Policy Center at Johns Hopkins University. Without their technical expertise and their determinations to help our laws keep pace with science, we would not be here today.

One other person who must be recognized is our good friend in the other body, Congresswoman LOUISE SLAUGHTER. Her determined leadership helped move us forward at every step of the way, and her tenacity and expertise will be essential to passage of this legislation in the House.

Nearly 2½ years ago, in one of his weekly radio addresses, President Bush joined in the call for comprehensive protection of genetic information. I urge all of our colleagues in the Senate to support this well-crafted, bipartisan solution. I also hope that our friends in the House will heed the President's words, follow this Senate's actions, and pass this bill quickly so we can get it to the President for his signature this year.

We cannot allow the gap between science and the law to continue to widen. We all have genetic markers. We are all potentially at risk of genetic discrimination. This is not a partisan issue. This is an urgent civil rights issue. There is no reason to wait any longer. We have a solution. We ought to pass it this year.

The PRESIDING OFFICER. The majority leader.

Mr. FRIST. Mr. President, we are about to vote on legislation that will provide important new protections against employment and health insurance discrimination based on genetic profiling. The bill protects Americans from both disease and discrimination.

We have been working on this legislation for many years, and I am pleased today that the Senate is about to act. I expect that today the Senate will overwhelmingly pass the genetic information nondiscrimination bill.

I especially commend my colleagues Senators SNOWE, GREGG, JEFFORDS, DASCHLE, KENNEDY, ENZI, HAGEL, COLLINS and DEWINE for their hard work and dedication over many years.

Since we began looking at the issue of genetic discrimination, genetic scholarship has advanced by leaps and bounds. This year, scientists, working in collaboration with the National Human Genome Research Institute at the National Institutes of Health, published a final draft of the sequence of the entire human genetic code.

It's a dazzling accomplishment that makes possible unprecedented under-

standing of human development, health and disease. It has the potential to change the way we practice medicine.

Scientists will be able to design drugs to treat specific genes. Tissues and organs may be specifically engineered for use in transplantation. Preventive care may potentially be based in large part on genetic testing. But this new knowledge is also fraught with risk.

When I first joined Senator SNOWE to address the issue of genetic discrimination, almost one-third of women offered a test for breast cancer risk at the National Institutes of Health declined, citing concerns that health insurance companies would discriminate against them.

They were afraid that genetic information gathered to protect them from disease might end up hurting their chances to get insurance.

Their fears were understandable. Genetic screening is a powerful tool, and can impart highly sensitive and very personal information. The fear of genetic discrimination has the potential to prevent individuals from participating in research studies, from taking advantage of new genetic technologies, or even from discovering that they are not at high risk for genetically related illnesses.

As a doctor and a Senator, I believe protecting our fellow citizens from genetic discrimination is a moral and practical responsibility.

In the past, Congress has taken on the battle against discrimination, most notably through the landmark 1964 Civil Rights Act, the 1990 Americans with Disabilities Act, and the Health Insurance Portability and Accountability Act.

This legislation stands squarely on our time-tested civil rights laws, establishing comprehensive, consistent, and fair protections.

Genetic research will make thrilling advances possible in the not too distant future, including possible cures to our most vexing illnesses.

But as we greet the future with new technology and scientific discoveries, we must take care to protect our body politic from unintended and unanticipated consequences. I am pleased by the progress we have made thus far, and I congratulate each of my colleagues on their dedication to this issue.

I strongly support the passage of this bill. It will help protect Americans from both discrimination and disease.

Mr. President, this is a bill we have worked on for the last 7 years. It has allowed us to address an issue, the human genome and the definition of the code, in advance. Everything we thought back then I believe was right on target. It has taken a long time to get to where we are today. It has taken a lot of bipartisan work among Senators on both sides of the aisle who really came down to wanting to pass a bill that did two things; that is, protect the health and the future health of

individuals in this country and, at the same time, protect from discrimination. This bill accomplishes that.

Again, I congratulate my colleagues for their leadership and persistence in passing this bill.

Mr. GREGG. Mr. President, I ask for the yeas and nays.

The PRESIDING OFFICER. Is there a sufficient second?

There is a sufficient second.

Under the previous order, the bill having been read the third time, the question is, Shall the bill, as amended, pass? The clerk will call the roll.

The assistant legislative clerk called the roll.

Mr. REID. I announce that the Senator from Minnesota (Mr. DAYTON), the Senator from North Carolina (Mr. EDWARDS), the Senator from Massachusetts (Mr. KERRY), the Senator from Connecticut (Mr. LIEBERMAN), and the Senator from Georgia (Mr. MILLER) are necessarily absent.

I further announce that, if present and voting, the Senator from Massachusetts (Mr. KERRY) would vote "Yea".

The PRESIDING OFFICER (Mr. CRAPO). Are there any other Senators in the Chamber desiring to vote?

The result was announced—yeas 95, nays 0, as follows:

[Rollcall Vote No. 377 Leg.]

YEAS—95

Akaka	Dodd	Lott
Alexander	Dole	Lugar
Allard	Domenici	McCain
Allen	Dorgan	McConnell
Baucus	Durbin	Mikulski
Bayh	Ensign	Murkowski
Bennett	Enzi	Murray
Biden	Feingold	Nelson (FL)
Bingaman	Feinstein	Nelson (NE)
Bond	Fitzgerald	Nickles
Boxer	Frist	Pryor
Breaux	Graham (FL)	Reed
Brownback	Graham (SC)	Reid
Bunning	Grassley	Roberts
Burns	Gregg	Rockefeller
Byrd	Hagel	Santorum
Campbell	Harkin	Sarbanes
Cantwell	Hatch	Schumer
Carper	Hollings	Sessions
Chafee	Hutchison	Shelby
Chambliss	Inhofe	Smith
Clinton	Inouye	Snowe
Cochran	Jeffords	Specter
Coleman	Johnson	Stabenow
Collins	Kennedy	Stevens
Conrad	Kohl	Sununu
Cornyn	Kyl	Talent
Corzine	Landrieu	Thomas
Craig	Lautenberg	Voinovich
Crapo	Leahy	Warner
Daschle	Levin	Wyden
DeWine	Lincoln	

NOT VOTING—5

Dayton	Kerry	Miller
Edwards	Lieberman	

The bill (S. 1053), as amended, was passed, as follows:

S. 1053

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the "Genetic Information Nondiscrimination Act of 2003".

(b) TABLE OF CONTENTS.—The table of contents of this Act is as follows:

Sec. 1. Short title; table of contents.
Sec. 2. Findings.

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

- Sec. 101. Amendments to Employee Retirement Income Security Act of 1974.
- Sec. 102. Amendments to the Public Health Service Act.
- Sec. 103. Amendments to the Internal Revenue Code of 1986.
- Sec. 104. Amendments to title XVIII of the Social Security Act relating to medigap.
- Sec. 105. Privacy and confidentiality.
- Sec. 106. Assuring coordination.
- Sec. 107. Regulations; effective date.

TITLE II—PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION

- Sec. 201. Definitions.
- Sec. 202. Employer practices.
- Sec. 203. Employment agency practices.
- Sec. 204. Labor organization practices.
- Sec. 205. Training programs.
- Sec. 206. Confidentiality of genetic information.
- Sec. 207. Remedies and enforcement.
- Sec. 208. Disparate impact.
- Sec. 209. Construction.
- Sec. 210. Medical information that is not genetic information.
- Sec. 211. Regulations.
- Sec. 212. Authorization of appropriations.
- Sec. 213. Effective date.

TITLE III—MISCELLANEOUS PROVISION

- Sec. 301. Severability.

SEC. 2. FINDINGS.

Congress makes the following findings:

(1) Deciphering the sequence of the human genome and other advances in genetics open major new opportunities for medical progress. New knowledge about the genetic basis of illness will allow for earlier detection of illnesses, often before symptoms have begun. Genetic testing can allow individuals to take steps to reduce the likelihood that they will contract a particular disorder. New knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment.

(2) The early science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic “defects” such as mental retardation, mental disease, epilepsy, blindness, and hearing loss, among other conditions. The first sterilization law was enacted in the State of Indiana in 1907. By 1981, a majority of States adopted sterilization laws to “correct” apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area.

(3) Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws

in the area, and in the early 1970s began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary.

(4) Congress has been informed of examples of genetic discrimination in the workplace. These include the use of pre-employment genetic screening at Lawrence Berkeley Laboratory, which led to a court decision in favor of the employees in that case *Norman Bloodsaw v. Lawrence Berkeley Laboratory* (135 F.3d 1260, 1269 (9th Cir. 1998)). Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance.

(5) Federal law addressing genetic discrimination in health insurance and employment is incomplete in both the scope and depth of its protections. Moreover, while many States have enacted some type of genetic non-discrimination law, these laws vary widely with respect to their approach, application, and level of protection. Congress has collected substantial evidence that the American public and the medical community find the existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination. Therefore Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

SEC. 101. AMENDMENTS TO EMPLOYEE RETIREMENT INCOME SECURITY ACT OF 1974.

(a) PROHIBITION OF HEALTH DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION OR GENETIC SERVICES.—

(1) NO ENROLLMENT RESTRICTION FOR GENETIC SERVICES.—Section 702(a)(1)(F) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182(a)(1)(F)) is amended by inserting before the period the following: “(including information about a request for or receipt of genetic services by an individual or family member of such individual)”.

(2) NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.—Section 702(b) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182(b)) is amended—

(A) in paragraph (2)(A), by inserting before the semicolon the following: “except as provided in paragraph (3)”;

(B) by adding at the end the following:

“(3) NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.—For purposes of this section, a group health plan, or a health insurance issuer offering group health insurance coverage in connection with a group health plan, shall not adjust premium or contribution amounts for a group on the basis of genetic information concerning an individual in the group or a family member of the individual (including information about a request for or receipt of genetic services by an individual or family member of such individual).”.

(b) LIMITATIONS ON GENETIC TESTING.—Section 702 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182) is amended by adding at the end the following:

“(c) GENETIC TESTING.—

“(1) LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.—A group health plan,

or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(2) RULE OF CONSTRUCTION.—Nothing in this part shall be construed to—

“(A) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;

“(B) limit the authority of a health care professional who is employed by or affiliated with a group health plan or a health insurance issuer and who is providing health care services to an individual as part of a bona fide wellness program to notify such individual of the availability of a genetic test or to provide information to such individual regarding such genetic test; or

“(C) authorize or permit a health care professional to require that an individual undergo a genetic test.

“(d) APPLICATION TO ALL PLANS.—The provisions of subsections (a)(1)(F), (b)(3), and (c) shall apply to group health plans and health insurance issuers without regard to section 732(a).”.

(c) REMEDIES AND ENFORCEMENT.—Section 502 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1132) is amended by adding at the end the following:

“(n) ENFORCEMENT OF GENETIC NONDISCRIMINATION REQUIREMENTS.—

“(1) INJUNCTIVE RELIEF FOR IRREPARABLE HARM.—With respect to any violation of subsection (a)(1)(F), (b)(3), or (c) of section 702, a participant or beneficiary may seek relief under subsection 502(a)(1)(B) prior to the exhaustion of available administrative remedies under section 503 if it is demonstrated to the court, by a preponderance of the evidence, that the exhaustion of such remedies would cause irreparable harm to the health of the participant or beneficiary. Any determinations that already have been made under section 503 in such case, or that are made in such case while an action under this paragraph is pending, shall be given due consideration by the court in any action under this subsection in such case.

“(2) EQUITABLE RELIEF FOR GENETIC NONDISCRIMINATION.—

“(A) REINSTATEMENT OF BENEFITS WHERE EQUITABLE RELIEF HAS BEEN AWARDED.—The recovery of benefits by a participant or beneficiary under a civil action under this section may include an administrative penalty under subparagraph (B) and the retroactive reinstatement of coverage under the plan involved to the date on which the participant or beneficiary was denied eligibility for coverage if—

“(i) the civil action was commenced under subsection (a)(1)(B); and

“(ii) the denial of coverage on which such civil action was based constitutes a violation of subsection (a)(1)(F), (b)(3), or (c) of section 702.

“(B) ADMINISTRATIVE PENALTY.—

“(i) IN GENERAL.—An administrator who fails to comply with the requirements of subsection (a)(1)(F), (b)(3), or (c) of section 702 with respect to a participant or beneficiary may, in an action commenced under subsection (a)(1)(B), be personally liable in the discretion of the court, for a penalty in the amount not more than \$100 for each day in the noncompliance period.

“(ii) NONCOMPLIANCE PERIOD.—For purposes of clause (i), the term ‘noncompliance period’ means the period—

“(I) beginning on the date that a failure described in clause (i) occurs; and

“(II) ending on the date that such failure is corrected.

“(iii) PAYMENT TO PARTICIPANT OR BENEFICIARY.—A penalty collected under this subparagraph shall be paid to the participant or beneficiary involved.

“(3) SECRETARIAL ENFORCEMENT AUTHORITY.—

“(A) GENERAL RULE.—The Secretary has the authority to impose a penalty on any failure of a group health plan to meet the requirements of subsection (a)(1)(F), (b)(3), or (c) of section 702.

“(B) AMOUNT.—

“(i) IN GENERAL.—The amount of the penalty imposed by subparagraph (A) shall be \$100 for each day in the noncompliance period with respect to each individual to whom such failure relates.

“(ii) NONCOMPLIANCE PERIOD.—For purposes of this paragraph, the term ‘noncompliance period’ means, with respect to any failure, the period—

“(I) beginning on the date such failure first occurs; and

“(II) ending on the date such failure is corrected.

“(C) MINIMUM PENALTIES WHERE FAILURE DISCOVERED.—Notwithstanding clauses (i) and (ii) of subparagraph (D):

“(i) IN GENERAL.—In the case of 1 or more failures with respect to an individual—

“(I) which are not corrected before the date on which the plan receives a notice from the Secretary of such violation; and

“(II) which occurred or continued during the period involved;

the amount of penalty imposed by subparagraph (A) by reason of such failures with respect to such individual shall not be less than \$2,500.

“(ii) HIGHER MINIMUM PENALTY WHERE VIOLATIONS ARE MORE THAN DE MINIMIS.—To the extent violations for which any person is liable under this paragraph for any year are more than de minimis, clause (i) shall be applied by substituting ‘\$15,000’ for ‘\$2,500’ with respect to such person.

“(D) LIMITATIONS.—

“(i) PENALTY NOT TO APPLY WHERE FAILURE NOT DISCOVERED EXERCISING REASONABLE DILIGENCE.—No penalty shall be imposed by subparagraph (A) on any failure during any period for which it is established to the satisfaction of the Secretary that the person otherwise liable for such penalty did not know, and exercising reasonable diligence would not have known, that such failure existed.

“(ii) PENALTY NOT TO APPLY TO FAILURES CORRECTED WITHIN CERTAIN PERIODS.—No penalty shall be imposed by subparagraph (A) on any failure if—

“(I) such failure was due to reasonable cause and not to willful neglect; and

“(II) such failure is corrected during the 30-day period beginning on the first date the person otherwise liable for such penalty knew, or exercising reasonable diligence would have known, that such failure existed.

“(iii) OVERALL LIMITATION FOR UNINTENTIONAL FAILURES.—In the case of failures which are due to reasonable cause and not to willful neglect, the penalty imposed by subparagraph (A) for failures shall not exceed the amount equal to the lesser of—

“(I) 10 percent of the aggregate amount paid or incurred by the employer (or predecessor employer) during the preceding taxable year for group health plans; or

“(II) \$500,000.

“(E) WAIVER BY SECRETARY.—In the case of a failure which is due to reasonable cause and not to willful neglect, the Secretary may waive part or all of the penalty imposed by subparagraph (A) to the extent that the payment of such penalty would be excessive relative to the failure involved.”.

(d) DEFINITIONS.—Section 733(d) of the Employee Retirement Income Security Act of

1974 (29 U.S.C. 1191b(d)) is amended by adding at the end the following:

“(5) FAMILY MEMBER.—The term ‘family member’ means with respect to an individual—

“(A) the spouse of the individual;

“(B) a dependent child of the individual, including a child who is born to or placed for adoption with the individual; and

“(C) all other individuals related by blood to the individual or the spouse or child described in subparagraph (A) or (B).

“(6) GENETIC INFORMATION.—

“(A) IN GENERAL.—Except as provided in subparagraph (B), the term ‘genetic information’ means information about—

“(i) an individual’s genetic tests;

“(ii) the genetic tests of family members of the individual; or

“(iii) the occurrence of a disease or disorder in family members of the individual.

“(B) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of an individual.

“(7) GENETIC TEST.—

“(A) IN GENERAL.—The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

“(B) EXCEPTIONS.—The term ‘genetic test’ does not mean—

“(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or

“(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

“(8) GENETIC SERVICES.—The term ‘genetic services’ means—

“(A) a genetic test;

“(B) genetic counseling (such as obtaining, interpreting, or assessing genetic information); or

“(C) genetic education.”.

(e) REGULATIONS AND EFFECTIVE DATE.—

(1) REGULATIONS.—Not later than 1 year after the date of enactment of this title, the Secretary of Labor shall issue final regulations in an accessible format to carry out the amendments made by this section.

(2) EFFECTIVE DATE.—The amendments made by this section shall apply with respect to group health plans for plan years beginning after the date that is 18 months after the date of enactment of this title.

SEC. 102. AMENDMENTS TO THE PUBLIC HEALTH SERVICE ACT.

(a) AMENDMENTS RELATING TO THE GROUP MARKET.—

(1) PROHIBITION OF HEALTH DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION OR GENETIC SERVICES.—

(A) NO ENROLLMENT RESTRICTION FOR GENETIC SERVICES.—Section 2702(a)(1)(F) of the Public Health Service Act (42 U.S.C. 300gg-1(a)(1)(F)) is amended by inserting before the period the following: “(including information about a request for or receipt of genetic services by an individual or family member of such individual)”.

(B) NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.—Section 2702(b) of the Public Health Service Act (42 U.S.C. 300gg-1(b)) is amended—

(i) in paragraph (2)(A), by inserting before the semicolon the following: “, except as provided in paragraph (3)”;

(ii) by adding at the end the following:

“(3) NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.—For purposes of this section, a group health plan, or a health insurance issuer offering group health insurance coverage in connection

with a group health plan, shall not adjust premium or contribution amounts for a group on the basis of genetic information concerning an individual in the group or a family member of the individual (including information about a request for or receipt of genetic services by an individual or family member of such individual).”.

(2) LIMITATIONS ON GENETIC TESTING.—Section 2702 of the Public Health Service Act (42 U.S.C. 300gg-1) is amended by adding at the end the following:

“(c) GENETIC TESTING.—

“(1) LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.—A group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(2) RULE OF CONSTRUCTION.—Nothing in this part shall be construed to—

“(A) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;

“(B) limit the authority of a health care professional who is employed by or affiliated with a group health plan or a health insurance issuer and who is providing health care services to an individual as part of a bona fide wellness program to notify such individual of the availability of a genetic test or to provide information to such individual regarding such genetic test; or

“(C) authorize or permit a health care professional to require that an individual undergo a genetic test.

“(d) APPLICATION TO ALL PLANS.—The provisions of subsections (a)(1)(F), (b)(3), and (c) shall apply to group health plans and health insurance issuers without regard to section 2721(a).”.

(3) REMEDIES AND ENFORCEMENT.—Section 2722(b) of the Public Health Service Act (42 U.S.C. 300gg-22(b)) is amended by adding at the end the following:

“(3) ENFORCEMENT AUTHORITY RELATING TO GENETIC DISCRIMINATION.—

“(A) GENERAL RULE.—In the cases described in paragraph (1), notwithstanding the provisions of paragraph (2)(C), the following provisions shall apply with respect to an action under this subsection by the Secretary with respect to any failure of a health insurance issuer in connection with a group health plan, to meet the requirements of subsection (a)(1)(F), (b)(3), or (c) of section 2702.

“(B) AMOUNT.—

“(i) IN GENERAL.—The amount of the penalty imposed under this paragraph shall be \$100 for each day in the noncompliance period with respect to each individual to whom such failure relates.

“(ii) NONCOMPLIANCE PERIOD.—For purposes of this paragraph, the term ‘noncompliance period’ means, with respect to any failure, the period—

“(I) beginning on the date such failure first occurs; and

“(II) ending on the date such failure is corrected.

“(C) MINIMUM PENALTIES WHERE FAILURE DISCOVERED.—Notwithstanding clauses (i) and (ii) of subparagraph (D):

“(i) IN GENERAL.—In the case of 1 or more failures with respect to an individual—

“(I) which are not corrected before the date on which the plan receives a notice from the Secretary of such violation; and

“(II) which occurred or continued during the period involved;

the amount of penalty imposed by subparagraph (A) by reason of such failures with respect to such individual shall not be less than \$2,500.

“(i) HIGHER MINIMUM PENALTY WHERE VIOLATIONS ARE MORE THAN DE MINIMIS.—To the extent violations for which any person is liable under this paragraph for any year are more than de minimis, clause (i) shall be applied by substituting ‘\$15,000’ for ‘\$2,500’ with respect to such person.

“(D) LIMITATIONS.—

“(i) PENALTY NOT TO APPLY WHERE FAILURE NOT DISCOVERED EXERCISING REASONABLE DILIGENCE.—No penalty shall be imposed by subparagraph (A) on any failure during any period for which it is established to the satisfaction of the Secretary that the person otherwise liable for such penalty did not know, and exercising reasonable diligence would not have known, that such failure existed.

“(ii) PENALTY NOT TO APPLY TO FAILURES CORRECTED WITHIN CERTAIN PERIODS.—No penalty shall be imposed by subparagraph (A) on any failure if—

“(I) such failure was due to reasonable cause and not to willful neglect; and

“(II) such failure is corrected during the 30-day period beginning on the first date the person otherwise liable for such penalty knew, or exercising reasonable diligence would have known, that such failure existed.

“(iii) OVERALL LIMITATION FOR UNINTENTIONAL FAILURES.—In the case of failures which are due to reasonable cause and not to willful neglect, the penalty imposed by subparagraph (A) for failures shall not exceed the amount equal to the lesser of—

“(I) 10 percent of the aggregate amount paid or incurred by the employer (or predecessor employer) during the preceding taxable year for group health plans; or

“(II) \$500,000.

“(E) WAIVER BY SECRETARY.—In the case of a failure which is due to reasonable cause and not to willful neglect, the Secretary may waive part or all of the penalty imposed by subparagraph (A) to the extent that the payment of such penalty would be excessive relative to the failure involved.”

(4) DEFINITIONS.—Section 2791(d) of the Public Health Service Act (42 U.S.C. 300gg-91(d)) is amended by adding at the end the following:

“(15) FAMILY MEMBER.—The term ‘family member’ means with respect to an individual—

“(A) the spouse of the individual;

“(B) a dependent child of the individual, including a child who is born to or placed for adoption with the individual; and

“(C) all other individuals related by blood to the individual or the spouse or child described in subparagraph (A) or (B).

“(16) GENETIC INFORMATION.—

“(A) IN GENERAL.—Except as provided in subparagraph (B), the term ‘genetic information’ means information about—

“(i) an individual’s genetic tests;

“(ii) the genetic tests of family members of the individual; or

“(iii) the occurrence of a disease or disorder in family members of the individual.

“(B) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of an individual.

“(17) GENETIC TEST.—

“(A) IN GENERAL.—The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

“(B) EXCEPTIONS.—The term ‘genetic test’ does not mean—

“(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or

“(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training

and expertise in the field of medicine involved.

“(18) GENETIC SERVICES.—The term ‘genetic services’ means—

“(A) a genetic test;

“(B) genetic counseling (such as obtaining, interpreting, or assessing genetic information); or

“(C) genetic education.”

(b) AMENDMENT RELATING TO THE INDIVIDUAL MARKET.—

(1) IN GENERAL.—The first subpart 3 of part B of title XXVII of the Public Health Service Act (42 U.S.C. 300gg-51 et seq.) (relating to other requirements) is amended—

(A) by redesignating such subpart as subpart 2; and

(B) by adding at the end the following:

“SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION.

“(a) PROHIBITION ON GENETIC INFORMATION AS A CONDITION OF ELIGIBILITY.—A health insurance issuer offering health insurance coverage in the individual market may not establish rules for the eligibility (including continued eligibility) of any individual to enroll in individual health insurance coverage based on genetic information (including information about a request for or receipt of genetic services by an individual or family member of such individual).

“(b) PROHIBITION ON GENETIC INFORMATION IN SETTING PREMIUM RATES.—A health insurance issuer offering health insurance coverage in the individual market shall not adjust premium or contribution amounts for an individual on the basis of genetic information concerning the individual or a family member of the individual (including information about a request for or receipt of genetic services by an individual or family member of such individual).

“(c) GENETIC TESTING.—

“(1) LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.—A health insurance issuer offering health insurance coverage in the individual market shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(2) RULE OF CONSTRUCTION.—Nothing in this part shall be construed to—

“(A) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;

“(B) limit the authority of a health care professional who is employed by or affiliated with a health insurance issuer and who is providing health care services to an individual as part of a bona fide wellness program to notify such individual of the availability of a genetic test or to provide information to such individual regarding such genetic test; or

“(C) authorize or permit a health care professional to require that an individual undergo a genetic test.”

(2) REMEDIES AND ENFORCEMENT.—Section 2761(b) of the Public Health Service Act (42 U.S.C. 300gg-61(b)) is amended to read as follows:

“(b) SECRETARIAL ENFORCEMENT AUTHORITY.—The Secretary shall have the same authority in relation to enforcement of the provisions of this part with respect to issuers of health insurance coverage in the individual market in a State as the Secretary has under section 2722(b)(2), and section 2722(b)(3) with respect to violations of genetic nondiscrimination provisions, in relation to the enforcement of the provisions of part A with respect to issuers of health insurance coverage in the small group market in the State.”

(c) ELIMINATION OF OPTION OF NON-FEDERAL GOVERNMENTAL PLANS TO BE EXCEPTED FROM

REQUIREMENTS CONCERNING GENETIC INFORMATION.—Section 2721(b)(2) of the Public Health Service Act (42 U.S.C. 300gg-21(b)(2)) is amended—

(1) in subparagraph (A), by striking “If the plan sponsor” and inserting “Except as provided in subparagraph (D), if the plan sponsor”; and

(2) by adding at the end the following:

“(D) ELECTION NOT APPLICABLE TO REQUIREMENTS CONCERNING GENETIC INFORMATION.—The election described in subparagraph (A) shall not be available with respect to the provisions of subsections (a)(1)(F) and (c) of section 2702 and the provisions of section 2702(b) to the extent that such provisions apply to genetic information (or information about a request for or the receipt of genetic services by an individual or a family member of such individual).”

(d) REGULATIONS AND EFFECTIVE DATE.—

(1) REGULATIONS.—Not later than 1 year after the date of enactment of this title, the Secretary of Labor and the Secretary of Health and Human Services (as the case may be) shall issue final regulations in an accessible format to carry out the amendments made by this section.

(2) EFFECTIVE DATE.—The amendments made by this section shall apply—

(A) with respect to group health plans, and health insurance coverage offered in connection with group health plans, for plan years beginning after the date that is 18 months after the date of enactment of this title; and

(B) with respect to health insurance coverage offered, sold, issued, renewed, in effect, or operated in the individual market after the date that is 18 months after the date of enactment of this title.

SEC. 103. AMENDMENTS TO THE INTERNAL REVENUE CODE OF 1986.

(a) PROHIBITION OF HEALTH DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION OR GENETIC SERVICES.—

(1) NO ENROLLMENT RESTRICTION FOR GENETIC SERVICES.—Section 9802(a)(1)(F) of the Internal Revenue Code of 1986 is amended by inserting before the period the following:

“(including information about a request for or receipt of genetic services by an individual or family member of such individual).”

(2) NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.—Section 9802(b) of the Internal Revenue Code of 1986 is amended—

(A) in paragraph (2)(A), by inserting before the semicolon the following: “, except as provided in paragraph (3)”; and

(B) by adding at the end the following:

“(3) NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.—For purposes of this section, a group health plan shall not adjust premium or contribution amounts for a group on the basis of genetic information concerning an individual in the group or a family member of the individual (including information about a request for or receipt of genetic services by an individual or family member of such individual).”

(b) LIMITATIONS ON GENETIC TESTING.—Section 9802 of the Internal Revenue Code of 1986 is amended by adding at the end the following:

“(d) GENETIC TESTING AND GENETIC SERVICES.—

“(1) LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.—A group health plan shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(2) RULE OF CONSTRUCTION.—Nothing in this part shall be construed to—

“(A) limit the authority of a health care professional who is providing health care

services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;

“(B) limit the authority of a health care professional who is employed by or affiliated with a group health plan and who is providing health care services to an individual as part of a bona fide wellness program to notify such individual of the availability of a genetic test or to provide information to such individual regarding such genetic test; or

“(C) authorize or permit a health care professional to require that an individual undergo a genetic test.

“(e) APPLICATION TO ALL PLANS.—The provisions of subsections (a)(1)(F), (b)(3), and (d) shall apply to group health plans and health insurance issuers without regard to section 9831(a)(2).”.

(c) DEFINITIONS.—Section 9832(d) of the Internal Revenue Code of 1986 is amended by adding at the end the following:

“(6) FAMILY MEMBER.—The term ‘family member’ means with respect to an individual—

“(A) the spouse of the individual;

“(B) a dependent child of the individual, including a child who is born to or placed for adoption with the individual; and

“(C) all other individuals related by blood to the individual or the spouse or child described in subparagraph (A) or (B).

“(7) GENETIC SERVICES.—The term ‘genetic services’ means—

“(A) a genetic test;

“(B) genetic counseling (such as obtaining, interpreting, or assessing genetic information); or

“(C) genetic education.

“(8) GENETIC INFORMATION.—

“(A) IN GENERAL.—Except as provided in subparagraph (B), the term ‘genetic information’ means information about—

“(i) an individual’s genetic tests;

“(ii) the genetic tests of family members of the individual; or

“(iii) the occurrence of a disease or disorder in family members of the individual.

“(B) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of an individual.

“(9) GENETIC TEST.—

“(A) IN GENERAL.—The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

“(B) EXCEPTIONS.—The term ‘genetic test’ does not mean—

“(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or

“(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.”.

(d) REGULATIONS AND EFFECTIVE DATE.—

(1) REGULATIONS.—Not later than 1 year after the date of enactment of this title, the Secretary of the Treasury shall issue final regulations in an accessible format to carry out the amendments made by this section.

(2) EFFECTIVE DATE.—The amendments made by this section shall apply with respect to group health plans for plan years beginning after the date that is 18 months after the date of enactment of this title.

SEC. 104. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SECURITY ACT RELATING TO MEDIGAP.

(a) NONDISCRIMINATION.—

(1) IN GENERAL.—Section 1882(s)(2) of the Social Security Act (42 U.S.C. 1395ss(s)(2)) is amended by adding at the end the following:

“(E)(i) An issuer of a medicare supplemental policy shall not deny or condition the issuance or effectiveness of the policy, and shall not discriminate in the pricing of the policy (including the adjustment of premium rates) of an eligible individual on the basis of genetic information concerning the individual (or information about a request for, or the receipt of, genetic services by such individual or family member of such individual).

“(ii) For purposes of clause (i), the terms ‘family member’, ‘genetic services’, and ‘genetic information’ shall have the meanings given such terms in subsection (v).”.

(2) EFFECTIVE DATE.—The amendment made by paragraph (1) shall apply with respect to a policy for policy years beginning after the date that is 18 months after the date of enactment of this Act.

(b) LIMITATIONS ON GENETIC TESTING.—

(1) IN GENERAL.—Section 1882 of the Social Security Act (42 U.S.C. 1395ss) is amended by adding at the end the following:

“(v) LIMITATIONS ON GENETIC TESTING.—

“(1) GENETIC TESTING.—

“(A) LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.—An issuer of a medicare supplemental policy shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(B) RULE OF CONSTRUCTION.—Nothing in this title shall be construed to—

“(i) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;

“(ii) limit the authority of a health care professional who is employed by or affiliated with an issuer of a medicare supplemental policy and who is providing health care services to an individual as part of a bona fide wellness program to notify such individual of the availability of a genetic test or to provide information to such individual regarding such genetic test; or

“(iii) authorize or permit a health care professional to require that an individual undergo a genetic test.

“(2) DEFINITIONS.—In this subsection:

“(A) FAMILY MEMBER.—The term ‘family member’ means with respect to an individual—

“(i) the spouse of the individual;

“(ii) a dependent child of the individual, including a child who is born to or placed for adoption with the individual; or

“(iii) any other individuals related by blood to the individual or to the spouse or child described in clause (i) or (ii).

“(B) GENETIC INFORMATION.—

“(i) IN GENERAL.—Except as provided in clause (ii), the term ‘genetic information’ means information about—

“(I) an individual’s genetic tests;

“(II) the genetic tests of family members of the individual; or

“(III) the occurrence of a disease or disorder in family members of the individual.

“(ii) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of an individual.

“(C) GENETIC TEST.—

“(i) IN GENERAL.—The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

“(ii) EXCEPTIONS.—The term ‘genetic test’ does not mean—

“(I) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or

“(II) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health

care professional with appropriate training and expertise in the field of medicine involved.

“(D) GENETIC SERVICES.—The term ‘genetic services’ means—

“(i) a genetic test;

“(ii) genetic counseling (such as obtaining, interpreting, or assessing genetic information); or

“(iii) genetic education.

“(E) ISSUER OF A MEDICARE SUPPLEMENTAL POLICY.—The term ‘issuer of a medicare supplemental policy’ includes a third-party administrator or other person acting for or on behalf of such issuer.”.

(2) CONFORMING AMENDMENT.—Section 1882(o) of the Social Security Act (42 U.S.C. 1395ss(o)) is amended by adding at the end the following:

“(4) The issuer of the medicare supplemental policy complies with subsection (s)(2)(E) and subsection (v).”.

(3) EFFECTIVE DATE.—The amendments made by this subsection shall apply with respect to an issuer of a medicare supplemental policy for policy years beginning on or after the date that is 18 months after the date of enactment of this Act.

(c) TRANSITION PROVISIONS.—

(1) IN GENERAL.—If the Secretary of Health and Human Services identifies a State as requiring a change to its statutes or regulations to conform its regulatory program to the changes made by this section, the State regulatory program shall not be considered to be out of compliance with the requirements of section 1882 of the Social Security Act due solely to failure to make such change until the date specified in paragraph (4).

(2) NAIC STANDARDS.—If, not later than June 30, 2004, the National Association of Insurance Commissioners (in this subsection referred to as the “NAIC”) modifies its NAIC Model Regulation relating to section 1882 of the Social Security Act (referred to in such section as the 1991 NAIC Model Regulation, as subsequently modified) to conform to the amendments made by this section, such revised regulation incorporating the modifications shall be considered to be the applicable NAIC model regulation (including the revised NAIC model regulation and the 1991 NAIC Model Regulation) for the purposes of such section.

(3) SECRETARY STANDARDS.—If the NAIC does not make the modifications described in paragraph (2) within the period specified in such paragraph, the Secretary of Health and Human Services shall, not later than October 1, 2004, make the modifications described in such paragraph and such revised regulation incorporating the modifications shall be considered to be the appropriate regulation for the purposes of such section.

(4) DATE SPECIFIED.—

(A) IN GENERAL.—Subject to subparagraph (B), the date specified in this paragraph for a State is the earlier of—

(i) the date the State changes its statutes or regulations to conform its regulatory program to the changes made by this section, or

(ii) October 1, 2004.

(B) ADDITIONAL LEGISLATIVE ACTION REQUIRED.—In the case of a State which the Secretary identifies as—

(i) requiring State legislation (other than legislation appropriating funds) to conform its regulatory program to the changes made in this section, but

(ii) having a legislation which is not scheduled to meet in 2004 in a legislative session in which such legislation may be considered, the date specified in this paragraph is the first day of the first calendar quarter beginning after the close of the first legislative session of the State legislature that begins

on or after July 1, 2004. For purposes of the previous sentence, in the case of a State that has a 2-year legislative session, each year of such session shall be deemed to be a separate regular session of the State legislature.

SEC. 105. PRIVACY AND CONFIDENTIALITY.

(a) **APPLICABILITY.**—Except as provided in subsection (d), the provisions of this section shall apply to group health plans, health insurance issuers (including issuers in connection with group health plans or individual health coverage), and issuers of medicare supplemental policies, without regard to—

(1) section 732(a) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1191a(a));

(2) section 2721(a) of the Public Health Service Act (42 U.S.C. 300gg-21(a)); and

(3) section 9831(a)(2) of the Internal Revenue Code of 1986.

(b) **COMPLIANCE WITH CERTAIN CONFIDENTIALITY STANDARDS WITH RESPECT TO GENETIC INFORMATION.**—

(1) **IN GENERAL.**—The regulations promulgated by the Secretary of Health and Human Services under part C of title XI of the Social Security Act (42 U.S.C. 1320d et seq.) and section 264 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d-2 note) shall apply to the use or disclosure of genetic information.

(2) **PROHIBITION ON UNDERWRITING AND PREMIUM RATING.**—Notwithstanding paragraph (1), a group health plan, a health insurance issuer, or issuer of a medicare supplemental policy shall not use or disclose genetic information (including information about a request for or a receipt of genetic services by an individual or family member of such individual) for purposes of underwriting, determinations of eligibility to enroll, premium rating, or the creation, renewal or replacement of a plan, contract or coverage for health insurance or health benefits.

(c) **PROHIBITION ON COLLECTION OF GENETIC INFORMATION.**—

(1) **IN GENERAL.**—A group health plan, health insurance issuer, or issuer of a medicare supplemental policy shall not request, require, or purchase genetic information (including information about a request for or a receipt of genetic services by an individual or family member of such individual) for purposes of underwriting, determinations of eligibility to enroll, premium rating, or the creation, renewal or replacement of a plan, contract or coverage for health insurance or health benefits.

(2) **LIMITATION RELATING TO THE COLLECTION OF GENETIC INFORMATION PRIOR TO ENROLLMENT.**—A group health plan, health insurance issuer, or issuer of a medicare supplemental policy shall not request, require, or purchase genetic information (including information about a request for or a receipt of genetic services by an individual or family member of such individual) concerning a participant, beneficiary, or enrollee prior to the enrollment, and in connection with such enrollment, of such individual under the plan, coverage, or policy.

(3) **INCIDENTAL COLLECTION.**—Where a group health plan, health insurance issuer, or issuer of a medicare supplemental policy obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning a participant, beneficiary, or enrollee, such request, requirement, or purchase shall not be considered a violation of this subsection if—

(A) such request, requirement, or purchase is not in violation of paragraph (1); and

(B) any genetic information (including information about a request for or receipt of genetic services) requested, required, or purchased is not used or disclosed in violation of subsection (b).

(d) **APPLICATION OF CONFIDENTIALITY STANDARDS.**—The provisions of subsections (b) and (c) shall not apply—

(1) to group health plans, health insurance issuers, or issuers of medicare supplemental policies that are not otherwise covered under the regulations promulgated by the Secretary of Health and Human Services under part C of title XI of the Social Security Act (42 U.S.C. 1320d et seq.) and section 264 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d-2 note); and

(2) to genetic information that is not considered to be individually-identifiable health information under the regulations promulgated by the Secretary of Health and Human Services under part C of title XI of the Social Security Act (42 U.S.C. 1320d et seq.) and section 264 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d-2 note).

(e) **ENFORCEMENT.**—A group health plan, health insurance issuer, or issuer of a medicare supplemental policy that violates a provision of this section shall be subject to the penalties described in sections 1176 and 1177 of the Social Security Act (42 U.S.C. 1320d-5 and 1320d-6) in the same manner and to the same extent that such penalties apply to violations of part C of title XI of such Act.

(f) **PREEMPTION.**—

(1) **IN GENERAL.**—A provision or requirement under this section or a regulation promulgated under this section shall supersede any contrary provision of State law unless such provision of State law imposes requirements, standards, or implementation specifications that are more stringent than the requirements, standards, or implementation specifications imposed under this section or such regulations. No penalty, remedy, or cause of action to enforce such a State law that is more stringent shall be preempted by this section.

(2) **RULE OF CONSTRUCTION.**—Nothing in paragraph (1) shall be construed to establish a penalty, remedy, or cause of action under State law if such penalty, remedy, or cause of action is not otherwise available under such State law.

(g) **COORDINATION WITH PRIVACY REGULATIONS.**—The Secretary shall implement and administer this section in a manner that is consistent with the implementation and administration by the Secretary of the regulations promulgated by the Secretary of Health and Human Services under part C of title XI of the Social Security Act (42 U.S.C. 1320d et seq.) and section 264 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d-2 note).

(h) **DEFINITIONS.**—In this section:

(1) **GENETIC INFORMATION; GENETIC SERVICES.**—The terms “family member”, “genetic information”, “genetic services”, and “genetic test” have the meanings given such terms in section 2791 of the Public Health Service Act (42 U.S.C. 300gg-91), as amended by this Act.

(2) **GROUP HEALTH PLAN; HEALTH INSURANCE ISSUER.**—The terms “group health plan” and “health insurance issuer” include only those plans and issuers that are covered under the regulations described in subsection (d)(1).

(3) **ISSUER OF A MEDICARE SUPPLEMENTAL POLICY.**—The term “issuer of a medicare supplemental policy” means an issuer described in section 1882 of the Social Security Act (42 U.S.C. 1395ss).

(4) **SECRETARY.**—The term “Secretary” means the Secretary of Health and Human Services.

SEC. 106. ASSURING COORDINATION.

(a) **IN GENERAL.**—Except as provided in subsection (b), the Secretary of the Treasury, the Secretary of Health and Human

Services, and the Secretary of Labor shall ensure, through the execution of an inter-agency memorandum of understanding among such Secretaries, that—

(1) regulations, rulings, and interpretations issued by such Secretaries relating to the same matter over which two or more such Secretaries have responsibility under this title (and the amendments made by this title) are administered so as to have the same effect at all times; and

(2) coordination of policies relating to enforcing the same requirements through such Secretaries in order to have a coordinated enforcement strategy that avoids duplication of enforcement efforts and assigns priorities in enforcement.

(b) **AUTHORITY OF THE SECRETARY.**—The Secretary of Health and Human Services has the sole authority to promulgate regulations to implement section 105.

SEC. 107. REGULATIONS; EFFECTIVE DATE.

(a) **REGULATIONS.**—Not later than 1 year after the date of enactment of this title, the Secretary of Labor, the Secretary of Health and Human Services, and the Secretary of the Treasury shall issue final regulations in an accessible format to carry out this title.

(b) **EFFECTIVE DATE.**—Except as provided in section 104, the amendments made by this title shall take effect on the date that is 18 months after the date of enactment of this Act.

TITLE II—PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION

SEC. 201. DEFINITIONS.

In this title:

(1) **COMMISSION.**—The term “Commission” means the Equal Employment Opportunity Commission as created by section 705 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-4).

(2) **EMPLOYEE; EMPLOYER; EMPLOYMENT AGENCY; LABOR ORGANIZATION; MEMBER.**—

(A) **IN GENERAL.**—The term “employee” means—

(i) an employee (including an applicant), as defined in section 701(f) of the Civil Rights Act of 1964 (42 U.S.C. 2000e(f));

(ii) a State employee (including an applicant) described in section 304(a) of the Government Employee Rights Act of 1991 (42 U.S.C. 2000e-16c(a));

(iii) a covered employee (including an applicant), as defined in section 101 of the Congressional Accountability Act of 1995 (2 U.S.C. 1301);

(iv) a covered employee (including an applicant), as defined in section 411(c) of title 3, United States Code; or

(v) an employee or applicant to which section 717(a) of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16(a)) applies.

(B) **EMPLOYER.**—The term “employer” means—

(i) an employer (as defined in section 701(b) of the Civil Rights Act of 1964 (42 U.S.C. 2000e(b)));

(ii) an entity employing a State employee described in section 304(a) of the Government Employee Rights Act of 1991;

(iii) an employing office, as defined in section 101 of the Congressional Accountability Act of 1995;

(iv) an employing office, as defined in section 411(c) of title 3, United States Code; or

(v) an entity to which section 717(a) of the Civil Rights Act of 1964 applies.

(C) **EMPLOYMENT AGENCY; LABOR ORGANIZATION.**—The terms “employment agency” and “labor organization” have the meanings given the terms in section 701 of the Civil Rights Act of 1964 (42 U.S.C. 2000e).

(D) **MEMBER.**—The term “member”, with respect to a labor organization, includes an applicant for membership in a labor organization.

(3) FAMILY MEMBER.—The term “family member” means with respect to an individual—

- (A) the spouse of the individual;
- (B) a dependent child of the individual, including a child who is born to or placed for adoption with the individual; and
- (C) all other individuals related by blood to the individual or the spouse or child described in subparagraph (A) or (B).

(4) GENETIC INFORMATION.—

(A) IN GENERAL.—Except as provided in subparagraph (B), the term “genetic information” means information about—

- (i) an individual’s genetic tests;
- (ii) the genetic tests of family members of the individual; or
- (iii) the occurrence of a disease or disorder in family members of the individual.

(B) EXCEPTIONS.—The term “genetic information” shall not include information about the sex or age of an individual.

(5) GENETIC MONITORING.—The term “genetic monitoring” means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace.

(6) GENETIC SERVICES.—The term “genetic services” means—

- (A) a genetic test;
- (B) genetic counseling (such as obtaining, interpreting or assessing genetic information); or
- (C) genetic education.

(7) GENETIC TEST.—

(A) IN GENERAL.—The term “genetic test” means the analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

(B) EXCEPTION.—The term “genetic test” does not mean an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes.

SEC. 202. EMPLOYER PRACTICES.

(a) USE OF GENETIC INFORMATION.—It shall be an unlawful employment practice for an employer—

(1) to fail or refuse to hire or to discharge any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information with respect to the employee (or information about a request for or the receipt of genetic services by such employee or family member of such employee); or

(2) to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of genetic information with respect to the employee (or information about a request for or the receipt of genetic services by such employee or family member of such employee).

(b) ACQUISITION OF GENETIC INFORMATION.—It shall be an unlawful employment practice for an employer to request, require, or purchase genetic information with respect to an employee or a family member of the employee (or information about a request for the receipt of genetic services by such employee or a family member of such employee) except—

(1) where an employer inadvertently requests or requires family medical history of the employee or family member of the employee;

(2) where—

(A) health or genetic services are offered by the employer, including such services offered as part of a bona fide wellness program;

(B) the employee provides prior, knowing, voluntary, and written authorization;

(C) only the employee (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and

(D) any individually identifiable genetic information provided under subparagraph (C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed to the employer except in aggregate terms that do not disclose the identity of specific employees;

(3) where an employer requests or requires family medical history from the employee to comply with the certification provisions of section 103 of the Family and Medical Leave Act of 1993 (29 U.S.C. 2613) or such requirements under State family and medical leave laws;

(4) where an employer purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history; or

(5) where the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace, but only if—

(A) the employer provides written notice of the genetic monitoring to the employee;

(B)(i) the employee provides prior, knowing, voluntary, and written authorization; or

(ii) the genetic monitoring is required by Federal or State law;

(C) the employee is informed of individual monitoring results;

(D) the monitoring is in compliance with—

- (i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the employer, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific employees;

(c) PRESERVATION OF PROTECTIONS.—In the case of information to which any of paragraphs (1) through (5) of subsection (b) applies, such information may not be used in violation of paragraph (1) or (2) of subsection (a) or treated or disclosed in a manner that violates section 206.

SEC. 203. EMPLOYMENT AGENCY PRACTICES.

(a) USE OF GENETIC INFORMATION.—It shall be an unlawful employment practice for an employment agency—

(1) to fail or refuse to refer for employment, or otherwise to discriminate against, any individual because of genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual);

(2) to limit, segregate, or classify individuals or fail or refuse to refer for employment

any individual in any way that would deprive or tend to deprive any individual of employment opportunities, or otherwise adversely affect the status of the individual as an employee, because of genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual); or

(3) to cause or attempt to cause an employer to discriminate against an individual in violation of this title.

(b) ACQUISITION OF GENETIC INFORMATION.—It shall be an unlawful employment practice for an employment agency to request, require, or purchase genetic information with respect to an individual or a family member of the individual (or information about a request for the receipt of genetic services by such individual or a family member of such individual) except—

(1) where an employment agency inadvertently requests or requires family medical history of the individual or family member of the individual;

(2) where—

(A) health or genetic services are offered by the employment agency, including such services offered as part of a bona fide wellness program;

(B) the individual provides prior, knowing, voluntary, and written authorization;

(C) only the individual (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and

(D) any individually identifiable genetic information provided under subparagraph (C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed to the employment agency except in aggregate terms that do not disclose the identity of specific individuals;

(3) where an employment agency requests or requires family medical history from the individual to comply with the certification provisions of section 103 of the Family and Medical Leave Act of 1993 (29 U.S.C. 2613) or such requirements under State family and medical leave laws;

(4) where an employment agency purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history; or

(5) where the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace, but only if—

(A) the employment agency provides written notice of the genetic monitoring to the individual;

(B)(i) the individual provides prior, knowing, voluntary, and written authorization; or

(ii) the genetic monitoring is required by Federal or State law;

(C) the individual is informed of individual monitoring results;

(D) the monitoring is in compliance with—

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the employment agency, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific individuals;

(c) **PRESERVATION OF PROTECTIONS.**—In the case of information to which any of paragraphs (1) through (5) of subsection (b) applies, such information may not be used in violation of paragraph (1) or (2) of subsection (a) or treated or disclosed in a manner that violates section 206.

SEC. 204. LABOR ORGANIZATION PRACTICES.

(a) **USE OF GENETIC INFORMATION.**—It shall be an unlawful employment practice for a labor organization—

(1) to exclude or to expel from the membership of the organization, or otherwise to discriminate against, any member because of genetic information with respect to the member (or information about a request for or the receipt of genetic services by such member or family member of such member);

(2) to limit, segregate, or classify the members of the organization, or fail or refuse to refer for employment any member, in any way that would deprive or tend to deprive any member of employment opportunities, or otherwise adversely affect the status of the member as an employee, because of genetic information with respect to the member (or information about a request for or the receipt of genetic services by such member or family member of such member); or

(3) to cause or attempt to cause an employer to discriminate against a member in violation of this title.

(b) **ACQUISITION OF GENETIC INFORMATION.**—It shall be an unlawful employment practice for a labor organization to request, require, or purchase genetic information with respect to a member or a family member of the member (or information about a request for the receipt of genetic services by such member or a family member of such member) except—

(1) where a labor organization inadvertently requests or requires family medical history of the member or family member of the member;

(2) where—

(A) health or genetic services are offered by the labor organization, including such services offered as part of a bona fide wellness program;

(B) the member provides prior, knowing, voluntary, and written authorization;

(C) only the member (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and

(D) any individually identifiable genetic information provided under subparagraph (C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed to the labor organization except in aggregate terms that do not disclose the identity of specific members;

(3) where a labor organization requests or requires family medical history from the members to comply with the certification provisions of section 103 of the Family and Medical Leave Act of 1993 (29 U.S.C. 2613) or such requirements under State family and medical leave laws;

(4) where a labor organization purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history; or

(5) where the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace, but only if—

(A) the labor organization provides written notice of the genetic monitoring to the member;

(B)(i) the member provides prior, knowing, voluntary, and written authorization; or

(ii) the genetic monitoring is required by Federal or State law;

(C) the member is informed of individual monitoring results;

(D) the monitoring is in compliance with—

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the labor organization, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific members;

(c) **PRESERVATION OF PROTECTIONS.**—In the case of information to which any of paragraphs (1) through (5) of subsection (b) applies, such information may not be used in violation of paragraph (1) or (2) of subsection (a) or treated or disclosed in a manner that violates section 206.

SEC. 205. TRAINING PROGRAMS.

(a) **USE OF GENETIC INFORMATION.**—It shall be an unlawful employment practice for any employer, labor organization, or joint labor-management committee controlling apprenticeship or other training or retraining, including on-the-job training programs—

(1) to discriminate against any individual because of genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or a family member of such individual) in admission to, or employment in, any program established to provide apprenticeship or other training or retraining;

(2) to limit, segregate, or classify the applicants for or participants in such apprenticeship or other training or retraining, or fail or refuse to refer for employment any individual, in any way that would deprive or tend to deprive any individual of employment opportunities, or otherwise adversely affect the status of the individual as an employee, because of genetic information with respect to the individual (or information about a request for or receipt of genetic services by such individual or family member of such individual); or

(3) to cause or attempt to cause an employer to discriminate against an applicant for or a participant in such apprenticeship or other training or retraining in violation of this title.

(b) **ACQUISITION OF GENETIC INFORMATION.**—It shall be an unlawful employment practice for an employer, labor organization, or joint labor-management committee described in subsection (a) to request, require, or purchase genetic information with respect to an individual or a family member of the individual (or information about a request for the receipt of genetic services by such individual or a family member of such individual) except—

(1) where the employer, labor organization, or joint labor-management committee inad-

vertently requests or requires family medical history of the individual or family member of the individual;

(2) where—

(A) health or genetic services are offered by the employer, labor organization, or joint labor-management committee, including such services offered as part of a bona fide wellness program;

(B) the individual provides prior, knowing, voluntary, and written authorization;

(C) only the individual (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services;

(D) any individually identifiable genetic information provided under subparagraph (C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed to the employer, labor organization, or joint labor-management committee except in aggregate terms that do not disclose the identity of specific individuals;

(3) where the employer, labor organization, or joint labor-management committee requests or requires family medical history from the individual to comply with the certification provisions of section 103 of the Family and Medical Leave Act of 1993 (29 U.S.C. 2613) or such requirements under State family and medical leave laws;

(4) where the employer, labor organization, or joint labor-management committee purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history; or

(5) where the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace, but only if—

(A) the employer, labor organization, or joint labor-management committee provides written notice of the genetic monitoring to the individual;

(B)(i) the individual provides prior, knowing, voluntary, and written authorization; or

(ii) the genetic monitoring is required by Federal or State law;

(C) the individual is informed of individual monitoring results;

(D) the monitoring is in compliance with—

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the employer, labor organization, or joint labor-management committee, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific individuals;

(c) **PRESERVATION OF PROTECTIONS.**—In the case of information to which any of paragraphs (1) through (5) of subsection (b) applies, such information may not be used in violation of paragraph (1) or (2) of subsection (a) or treated or disclosed in a manner that violates section 206.

SEC. 206. CONFIDENTIALITY OF GENETIC INFORMATION.

(a) **TREATMENT OF INFORMATION AS PART OF CONFIDENTIAL MEDICAL RECORD.**—If an employer, employment agency, labor organization, or joint labor-management committee possesses genetic information about an employee or member (or information about a request for or receipt of genetic services by such employee or member or family member of such employee or member), such information shall be maintained on separate forms and in separate medical files and be treated as a confidential medical record of the employee or member.

(b) **LIMITATION ON DISCLOSURE.**—An employer, employment agency, labor organization, or joint labor-management committee shall not disclose genetic information concerning an employee or member (or information about a request for or receipt of genetic services by such employee or member or family member of such employee or member) except—

(1) to the employee (or family member if the family member is receiving the genetic services) or member of a labor organization at the request of the employee or member of such organization;

(2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;

(3) in response to an order of a court, except that—

(A) the employer, employment agency, labor organization, or joint labor-management committee may disclose only the genetic information expressly authorized by such order; and

(B) if the court order was secured without the knowledge of the employee or member to whom the information refers, the employer, employment agency, labor organization, or joint labor-management committee shall provide the employee or member with adequate notice to challenge the court order;

(4) to government officials who are investigating compliance with this title if the information is relevant to the investigation; or

(5) to the extent that such disclosure is made in connection with the employee's compliance with the certification provisions of section 103 of the Family and Medical Leave Act of 1993 (29 U.S.C. 2613) or such requirements under State family and medical leave laws.

SEC. 207. REMEDIES AND ENFORCEMENT.

(a) **EMPLOYEES COVERED BY TITLE VII OF THE CIVIL RIGHTS ACT OF 1964.**—

(1) **IN GENERAL.**—The powers, remedies, and procedures provided in sections 705, 706, 707, 709, 710, and 711 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-4 et seq.) to the Commission, the Attorney General, or any person, alleging a violation of title VII of that Act (42 U.S.C. 2000e et seq.) shall be the powers, remedies, and procedures this title provides to the Commission, the Attorney General, or any person, respectively, alleging an unlawful employment practice in violation of this title against an employee described in section 201(2)(A)(i), except as provided in paragraphs (2) and (3).

(2) **COSTS AND FEES.**—The powers, remedies, and procedures provided in subsections (b) and (c) of section 722 of the Revised Statutes (42 U.S.C. 1988), shall be powers, remedies, and procedures this title provides to the Commission, the Attorney General, or any person, alleging such a practice.

(3) **DAMAGES.**—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to

the Commission, the Attorney General, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes).

(b) **EMPLOYEES COVERED BY GOVERNMENT EMPLOYEE RIGHTS ACT OF 1991.**—

(1) **IN GENERAL.**—The powers, remedies, and procedures provided in sections 302 and 304 of the Government Employee Rights Act of 1991 (42 U.S.C. 2000e-16b, 2000e-16c) to the Commission, or any person, alleging a violation of section 302(a)(1) of that Act (42 U.S.C. 2000e-16b(a)(1)) shall be the powers, remedies, and procedures this title provides to the Commission, or any person, respectively, alleging an unlawful employment practice in violation of this title against an employee described in section 201(2)(A)(ii), except as provided in paragraphs (2) and (3).

(2) **COSTS AND FEES.**—The powers, remedies, and procedures provided in subsections (b) and (c) of section 722 of the Revised Statutes (42 U.S.C. 1988), shall be powers, remedies, and procedures this title provides to the Commission, or any person, alleging such a practice.

(3) **DAMAGES.**—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to the Commission, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes).

(c) **EMPLOYEES COVERED BY CONGRESSIONAL ACCOUNTABILITY ACT OF 1995.**—

(1) **IN GENERAL.**—The powers, remedies, and procedures provided in the Congressional Accountability Act of 1995 (2 U.S.C. 1301 et seq.) to the Board (as defined in section 101 of that Act (2 U.S.C. 1301)), or any person, alleging a violation of section 201(a)(1) of that Act (42 U.S.C. 1311(a)(1)) shall be the powers, remedies, and procedures this title provides to that Board, or any person, alleging an unlawful employment practice in violation of this title against an employee described in section 201(2)(A)(iii), except as provided in paragraphs (2) and (3).

(2) **COSTS AND FEES.**—The powers, remedies, and procedures provided in subsections (b) and (c) of section 722 of the Revised Statutes (42 U.S.C. 1988), shall be powers, remedies, and procedures this title provides to that Board, or any person, alleging such a practice.

(3) **DAMAGES.**—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to that Board, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes).

(4) **OTHER APPLICABLE PROVISIONS.**—With respect to a claim alleging a practice described in paragraph (1), title III of the Congressional Accountability Act of 1995 (2 U.S.C. 1381 et seq.) shall apply in the same manner as such title applies with respect to a claim alleging a violation of section 201(a)(1) of such Act (2 U.S.C. 1311(a)(1)).

(d) **EMPLOYEES COVERED BY CHAPTER 5 OF TITLE 3, UNITED STATES CODE.**—

(1) **IN GENERAL.**—The powers, remedies, and procedures provided in chapter 5 of title 3, United States Code, to the President, the Commission, the Merit Systems Protection Board, or any person, alleging a violation of section 411(a)(1) of that title, shall be the powers, remedies, and procedures this title provides to the President, the Commission, such Board, or any person, respectively, al-

leging an unlawful employment practice in violation of this title against an employee described in section 201(2)(A)(iv), except as provided in paragraphs (2) and (3).

(2) **COSTS AND FEES.**—The powers, remedies, and procedures provided in subsections (b) and (c) of section 722 of the Revised Statutes (42 U.S.C. 1988), shall be powers, remedies, and procedures this title provides to the President, the Commission, such Board, or any person, alleging such a practice.

(3) **DAMAGES.**—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to the President, the Commission, such Board, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes).

(e) **EMPLOYEES COVERED BY SECTION 717 OF THE CIVIL RIGHTS ACT OF 1964.**—

(1) **IN GENERAL.**—The powers, remedies, and procedures provided in section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16) to the Commission, the Attorney General, the Librarian of Congress, or any person, alleging a violation of that section shall be the powers, remedies, and procedures this title provides to the Commission, the Attorney General, the Librarian of Congress, or any person, respectively, alleging an unlawful employment practice in violation of this title against an employee or applicant described in section 201(2)(A)(v), except as provided in paragraphs (2) and (3).

(2) **COSTS AND FEES.**—The powers, remedies, and procedures provided in subsections (b) and (c) of section 722 of the Revised Statutes (42 U.S.C. 1988), shall be powers, remedies, and procedures this title provides to the Commission, the Attorney General, the Librarian of Congress, or any person, alleging such a practice.

(3) **DAMAGES.**—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to the Commission, the Attorney General, the Librarian of Congress, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes).

(f) **DEFINITION.**—In this section, the term "Commission" means the Equal Employment Opportunity Commission.

SEC. 208. DISPARATE IMPACT.

(a) **GENERAL RULE.**—Notwithstanding any other provision of this Act, "disparate impact", as that term is used in section 703(k) of the Civil Rights Act of 1964 (42 U.S.C. 2000e-d(k)), on the basis of genetic information does not establish a cause of action under this Act.

(b) **COMMISSION.**—On the date that is 6 years after the date of enactment of this Act, there shall be established a commission, to be known as the Genetic Nondiscrimination Study Commission (referred to in this section as the "Commission") to review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act.

(c) **MEMBERSHIP.**—

(1) **IN GENERAL.**—The Commission shall be composed of 8 members, of which—

(A) 1 member shall be appointed by the Majority Leader of the Senate;

(B) 1 member shall be appointed by the Minority Leader of the Senate;

(C) 1 member shall be appointed by the Chairman of the Committee on Health, Education, Labor, and Pensions of the Senate;

(D) 1 member shall be appointed by the ranking minority member of the Committee on Health, Education, Labor, and Pensions of the Senate;

(E) 1 member shall be appointed by the Speaker of the House of Representatives;

(F) 1 member shall be appointed by the Minority Leader of the House of Representatives;

(G) 1 member shall be appointed by the Chairman of the Committee on Education and the Workforce of the House of Representatives; and

(H) 1 member shall be appointed by the ranking minority member of the Committee on Education and the Workforce of the House of Representatives.

(2) **COMPENSATION AND EXPENSES.**—The members of the Commission shall not receive compensation for the performance of services for the Commission, but shall be allowed travel expenses, including per diem in lieu of subsistence, at rates authorized for employees of agencies under subchapter I of chapter 57 of title 5, United States Code, while away from their homes or regular places of business in the performance of services for the Commission.

(d) **ADMINISTRATIVE PROVISIONS.**—

(1) **LOCATION.**—The Commission shall be located in a facility maintained by the Equal Employment Opportunity Commission.

(2) **DETAIL OF GOVERNMENT EMPLOYEES.**—Any Federal Government employee may be detailed to the Commission without reimbursement, and such detail shall be without interruption or loss of civil service status or privilege.

(3) **INFORMATION FROM FEDERAL AGENCIES.**—The Commission may secure directly from any Federal department or agency such information as the Commission considers necessary to carry out the provisions of this section. Upon request of the Commission, the head of such department or agency shall furnish such information to the Commission.

(4) **HEARINGS.**—The Commission may hold such hearings, sit and act at such times and places, take such testimony, and receive such evidence as the Commission considers advisable to carry out the objectives of this section, except that, to the extent possible, the Commission shall use existing data and research.

(5) **POSTAL SERVICES.**—The Commission may use the United States mails in the same manner and under the same conditions as other departments and agencies of the Federal Government.

(e) **REPORT.**—Not later than 1 year after all of the members are appointed to the Commission under subsection (c)(1), the Commission shall submit to Congress a report that summarizes the findings of the Commission and makes such recommendations for legislation as are consistent with this Act.

(f) **AUTHORIZATION OF APPROPRIATIONS.**—There are authorized to be appropriated to the Equal Employment Opportunity Commission such sums as may be necessary to carry out this section.

SEC. 209. CONSTRUCTION.

Nothing in this title shall be construed to—

(1) limit the rights or protections of an individual under the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), including coverage afforded to individuals under section 102 of such Act (42 U.S.C. 12112), or under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.);

(2)(A) limit the rights or protections of an individual to bring an action under this title against an employer, employment agency,

labor organization, or joint labor-management committee for a violation of this title; or

(B) establish a violation under this title for an employer, employment agency, labor organization, or joint labor-management committee of a provision of the amendments made by title I;

(3) limit the rights or protections of an individual under any other Federal or State statute that provides equal or greater protection to an individual than the rights or protections provided for under this title;

(4) apply to the Armed Forces Repository of Specimen Samples for the Identification of Remains;

(5) limit or expand the protections, rights, or obligations of employees or employers under applicable workers' compensation laws;

(6) limit the authority of a Federal department or agency to conduct or sponsor occupational or other health research that is conducted in compliance with the regulations contained in part 46 of title 45, Code of Federal Regulations (or any corresponding or similar regulation or rule); and

(7) limit the statutory or regulatory authority of the Occupational Safety and Health Administration or the Mine Safety and Health Administration to promulgate or enforce workplace safety and health laws and regulations.

SEC. 210. MEDICAL INFORMATION THAT IS NOT GENETIC INFORMATION.

An employer, employment agency, labor organization, or joint labor-management committee shall not be considered to be in violation of this title based on the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee or member, including a manifested disease, disorder, or pathological condition that has or may have a genetic basis.

SEC. 211. REGULATIONS.

Not later than 1 year after the date of enactment of this title, the Commission shall issue final regulations in an accessible format to carry out this title.

SEC. 212. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated such sums as may be necessary to carry out this title (except for section 208).

SEC. 213. EFFECTIVE DATE.

This title takes effect on the date that is 18 months after the date of enactment of this Act.

TITLE III—MISCELLANEOUS PROVISION

SEC. 301. SEVERABILITY.

If any provision of this Act, an amendment made by this Act, or the application of such provision or amendment to any person or circumstance is held to be unconstitutional, the remainder of this Act, the amendments made by this Act, and the application of such provisions to any person or circumstance shall not be affected thereby.

Mr. STEVENS. I move to reconsider the vote and I move to lay that motion on the table.

The motion to lay on the table was agreed to.

EMERGENCY SUPPLEMENTAL APPROPRIATIONS FOR IRAQ AND AFGHANISTAN SECURITY AND RECONSTRUCTION ACT, 2004—Continued

AMENDMENT NO. 1830

The PRESIDING OFFICER. There are 4 minutes equally divided on the Bingaman amendment.

Mr. STEVENS. This is a very serious amendment.

Parliamentary inquiry. There are 2 minutes on each side on the Bingaman amendment?

The PRESIDING OFFICER. The Senator is correct.

Mr. STEVENS. Does the Senator wish to speak first?

Mr. BINGAMAN. I will defer to the Senator from Alaska.

Mr. STEVENS. I will yield our time to Senator WARNER, chairman of the Armed Services Committee.

Mr. WARNER. Go right ahead.

Mr. BINGAMAN. Mr. President, in previous military campaigns such as the first gulf war and Kosovo, and many before that, the Pentagon has issued campaign medals to service men and women who served in those conflicts. We need to do the very same in the case of our service men and women who are serving in Iraq.

The amendment I am proposing says the Secretaries of the respective services may issue an appropriate medal or campaign designation to any person who serves in any capacity in the armed services in connection with Operation Iraqi Freedom. In my view, this is much preferable to the Pentagon's current policy, which is that everyone should get a Global War on Terrorism Medal instead of a medal that relates to their service in Iraq.

The service men and women who are risking their lives in Iraq deserve to be recognized for their service in that country. This is a major military engagement we have gotten into here and there will be a lot of service men and women involved. We definitely should make this a separate medal.

That is the thrust of the amendment. Senator LUGAR is a cosponsor, along with many others. I ask unanimous consent to add Senators BYRD, LEAHY, and JEFFORDS to those who are already listed as cosponsors.

The PRESIDING OFFICER. Without objection, it is so ordered.

Mr. WARNER. Mr. President, I say to my colleagues, I would like to think of myself as the last person to ever take the floor of the Senate and say a man or a woman proudly wearing the uniform of the United States should not receive everything that is offered. But in this instance—I do not oppose this—I simply ask you to examine it in the sense of fairness. What do you say to the widow of someone who lost his life in Afghanistan? What do you say to those who have injured soldiers in the Horn of Africa, Liberia, Philippines, Colombia, and other places, all engaged in the war on terrorism?

I do not understand this. I have read it. I have reread it. It says, for example, to those serving in Iraq, prohibition of concurrent award of Global War on Terrorism Expeditionary Medal. They cannot receive it. For what reason, I do not know.

I say to my dear friend, a former member of the Armed Services Committee, this is a matter that requires